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ABSTRACT

Presented is a report on the current status of implementation of the Presidential goal (made in 1971) to reduce by half the incidence of mental retardation by the end of this century. Major conclusions are as follows: no major agency of the Department of Health, Education, and Welfare (HEW) has been made responsible for seeing that the goal is put into practice, coordinating efforts, clarifying agency roles and resource commitments, and measuring progress in meeting the goal; prevention of mental retardation has not been designated an objective by HEW's agencies responsible for prevention; and systems have not been established or methods developed to assess progress in achieving the goal. Chapters focus on the following topics: mental retardation and its causes, improvements needed in HEW administration of the prevention effort, expanding newborn screening for metabolic disorders, improving prenatal care to reduce prematurity and low birth weight, identifying persons in need of genetic testing and counseling, improving immunization levels for rubella and measles, increased screening to detect lead poisoning, expanding testing and immunization to prevent Rh disease, and improving early childhood experiences. Conclusions, recommendations, and HEW comments follow the discussion in each chapter. Appended are such items as a list of the principal HEW officials responsible for activities discussed in the report. (DB)

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REPORT TO THE CONGRESS

BY THE COMPTROLLER GENERAL OF THE UNITED STATES

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

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Preventing Mental Retardation--More Can Be Done

No Federal agency is coordinating a national strategy to prevent mental retardation or directing Federal resources toward prevention.

Much more can be done by the the Department of Health, Education, and Welfare to reduce mental retardation caused by metabolic disorders, insufficient prenatal care, chromosome abnormalities, rubella and measles, lead poisoning, Rh hemolytic diseases, and early childhood experiences.

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OCTOBER 3, 1977

COMPTROLLER GENERAL OF THE UNITED STATES
WASHINGTON, D.C. 20548

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To the President of the Senate and the
Speaker of the House of Representatives

This report discusses the implementation of a Presidential goal to reduce by half the incidence of mental retardation by the end of this century. It discusses the need to designate a specific group within the Department of Health, Education, and Welfare with responsibility for implementing and monitoring a national prevention strategy, clarifying agency roles, and determining which and how the Department's programs can best assist in the effort. The report also discusses what else can be done to reduce mental retardation resulting from selected causes.

Our review was made to determine what progress was being made in reducing the incidence of mental retardation and to determine what else could be done. We made our review pursuant to the Budget and Accounting Act, 1921 (31 U.S.C. 53), and the Accounting and Auditing Act of 1950 (31 U.S.C. 67).

We are sending copies of this report to the Director, Office of Management and Budget, and the Secretary of Health, Education, and Welfare.

Comptroller General
of the United States

COMPTROLLER GENERAL'S REPORT TO THE CONGRESS

PREVENTING MENTAL RETARDATION--MORE CAN BE DONE

D I G E S T

In November 1971 the President established a national goal: to reduce by half the incidence of mental retardation by the end of the century. Despite this goal:

--No agency of the Department of Health, Education, and Welfare (HEW) has been made responsible for seeing that the goal is put into practice, coordinating efforts, clarifying agency roles and resource commitments, or measuring progress in meeting the goal.

--Prevention of mental retardation has not been designated an objective by the Department's agencies responsible for prevention.

--Systems have not been established or methods developed to assess progress in achieving the goal. (See ch. 2.)

Many authorities believe that about 6 million Americans are retarded and as many as 4 million of the children expected to be born by the year 2000 will be mentally retarded.

HEW estimates that mental retardation costs the Nation between $6.5 and $9 billion annually in care, treatment, and lost productivity. HEW alone spent over $1.7 billion on the mentally retarded in fiscal year 1976.

Of the many causes of mental retardation which have been identified, GAO selected a few for which preventive techniques are available to determine what else can be done. Many causes of retardation also have other ill effects. Thus, if the incidence of retardation is reduced, these problems may also be prevented, possibly saving lives

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and avoiding human suffering. Following are the causes GAO selected.

METABOLIC DISORDERS

Mental retardation caused by inherited metabolic disorders can often be prevented if the afflicted infant is identified and treated shortly after birth. Almost all States have programs for testing a blood sample from newborn infants to detect phenylketonuria. 1/ To reach all newborn infants, improvements are needed in many of these programs. Also, only a limited number of States are testing for six other treatable metabolic disorders which can be identified from the same blood sample.

Although these metabolic disorders are not common, the monetary savings that result from avoided costs of caring for the retarded greatly exceed the cost of screening all newborn infants and treating them. Also, by using automated laboratory methods applied on a large scale, tests for other disorders can be made on the blood sample drawn for phenylketonuria testing at little or no additional cost. (See ch. 3.)

PREMATURITY AND LOW BIRTH WEIGHT

Comprehensive prenatal care can help prevent low birth weight and prematurity, reducing the incidence of mental retardation. However, many women receive no prenatal care and many more do not obtain prenatal care until very late in pregnancy.

Health officials in each State visited said additional prenatal care was needed. However, in these States the extent of the unmet need for prenatal care, location of those areas most in need, or the effect

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1/A metabolic disorder caused by the inability to produce the enzyme which ordinarily metabolizes a particular protein in foods.

prenatal care programs have had on reducing mental retardation have not been sufficiently analyzed.

HEW has not evaluated State programs to assess how they affect the population served or to make sure that resources are being used most effectively. (See ch. 4.)

CHROMOSOME ABNORMALITIES

Chromosome abnormalities are estimated to account for about 16 percent of the clinically caused cases of mental retardation. Down's syndrome, one of the commonest of such abnormalities, appears in about 5,000 births each year and, although current information is not available, it has accounted for 15 to 20 percent of the institutionalized mentally retarded.

Treatment of chromosome abnormalities is limited; thus, medical genetics concentrates on preventing retardation through genetic counseling and testing. However, only a small portion of those who could benefit from these services receive them. Neither HEW nor the States attempted to find out if persons needing the service are screened or served. Geneticists interviewed generally thought that a disproportionately small number of those who obtain genetic services were from lower socioeconomic groups.

Federally funded family planning programs and possibly others could provide the needed outreach, identification, and services to lower income families. Federally funded maternity and infant care projects were referring high-risk clients for genetic services; however, the family planning programs in those States generally did not.

RUBELLA AND MEASLES

Mental retardation caused by rubella and measles can be prevented by aggressive vaccination programs. But, because rubella

and measles immunization levels are low, expanded efforts to immunize children and test women of childbearing age for susceptibility to rubella are needed. Better data is needed on immunity levels in local areas. Certain Federal programs--such as Medicaid's Early and Periodic Screening, Diagnosis, and Treatment; Head Start; and family planning--could help improve surveillance data and raise immunity levels. (See ch. 6.)

LEAD POISONING

HEW estimates that 600,000 children have elevated blood lead levels. More widespread screening is needed to determine the extent of the lead poisoning problem. A recent breakthrough in testing techniques has made it possible to do more testing inexpensively.

However, except in certain known high-risk areas, lead poisoning is not recognized as a problem and screening is not routinely done. Reporting requirements are inadequate to determine the extent of screening or the results in locales where screening is done. (See ch. 7.)

Rh HEMOLYTIC DISEASE

Mental retardation and other complications caused by Rh hemolytic disease can be prevented by identifying women with Rh negative blood types and providing them with immunoglobulin when they bear Rh positive children or have abortions. Although the extent of the problem is not known, many women apparently are not receiving the immunoglobulin.

States need comprehensive systems for testing pregnant women for Rh incompatability, reporting disease incidence, and reporting immunoglobulin utilization. Only five States had mechanisms for fully monitoring Rh hemolytic disease, only seven required either premarital or prenatal blood typing,

and only six had special programs for reporting immunoglobulin use. In lieu of State laws requiring such tests, the family planning programs could assist by including Rh blood typing as a routine part of family planning services. (See ch. 8.)

EARLY CHILDHOOD EXPERIENCES

About 75 percent of the incidence of mental retardation is attributed to environmental conditions during early childhood. Although the relationship between poor living conditions and mental retardation is still not fully understood, many projects are studying this.

So far, this work has not been organized at either the Federal or State level. HEW agencies did not feel it was their responsibility to collect and evaluate the results of various programs directed at preventing psychosocial retardation or implementing those that are the most efficient and effective. As a result, little is known about the full extent of ongoing programs, the number of people being reached, or whether or not the techniques being used are effective and could be more widely applied. (See ch. 9.)

RECOMMENDATIONS

The Secretary of HEW should (1) designate a focal point in the Department to implement a national prevention strategy, monitor and coordinate the efforts of the various HEW agencies and offices, and develop a method of determining the progress being made in reaching the goal and (2) make the prevention of mental retardation an objective in HEW's operational planning system. (See p. 20.)

This report makes several recommendations to the Secretary on actions that could be taken to increase HEW's efforts to reduce mental retardation caused by metabolic

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disorders, insufficient prenatal care, genetic disorders, rubella and measles, lead poisoning, Rh hemolytic disease, and poor early childhood experiences. (See pp. 33, 42, 50, 60, 70, 78, and 85.)

AGENCY COMMENTS

HEW generally agreed with GAO's findings and recommendations and stated that the conclusions were valid and the recommendations worthy of implementation.

HEW told GAO that it would designate the Office of Assistant Secretary for Health as the focal point in the Department for mental retardation prevention. It agreed that, whether or not its operational planning system is continued, the relevant issues would be monitored by the agency tracking system. HEW also pointed out several actions it was taking in response to other GAO recommendations. (See pp. 87 to 96.)

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ABBREVIATIONS

CDC	Center for Disease Control
EPSDT	Early and Periodic Screening, Diagnosis, and Treatment
FEP	free erythrocyte protoporphyrin
GAO	General Accounting Office
HEW	Department of Health, Education, and Welfare
PCMR	President's Committee on Mental Retardation
PKU	phenylketonuria

CHAPTER 1

MENTAL RETARDATION AND ITS CAUSES

Mental retardation is one of the Nation's greatest long-term public health, social, and economic problems. Although precise data on the extent of mental retardation in the United States is not available, authorities estimate that over 6 million persons are mentally retarded and that over 100,000 new cases of retardation occur each year. Some estimate that as many as 4 million of the 80 million children expected to be born (at present birth rates) by the year 2000 will be or become retarded.

In 1974 the Department of Health, Education, and Welfare (HEW) estimated the national cost of mental retardation at between $8.5 and $9 billion annually, including care, treatment, and the economic losses attributable to the decreased productivity of the retarded. HEW estimated that it alone spent over $1.7 billion in fiscal year 1976 for the mentally retarded. The President's Committee on Mental Retardation (PCMR) estimates that if the number of persons who are severely or profoundly retarded (about 5 percent of the total) could be reduced by half by the year 2000, the annual savings would be $2.7 billion.

In 1971 PCMR declared that, by using present knowledge and techniques from the biomedical and behavioral sciences, the occurrence of mental retardation could be reduced by 50 percent by the end of this century. Later that year, President Nixon adopted this figure as a national goal. President Ford reaffirmed the goal in 1974. In 1976, PCMR called for reducing the incidence of mental retardation (1) from biomedical causes by at least 50 percent by the year 2000 and (2) associated with social disadvantage to the lowest level possible by the end of the century. The Committee reported:

> "* * * If the American people have the will to achieve this goal, it can be done--but it will require a serious and sustained effort to apply the means that are available. To reach the halfway mark in the next 25 years is entirely feasible with the knowledge that we now have. To exceed the President's goal for this century is quite possible if we expand knowledge and apply it at the rate we have done in the past 25 years."

The Congress has recognized the importance and benefits of preventing mental retardation through the many laws enacted or under consideration which deal directly or indirectly with preventing retardation. These include the National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs and Genetic Diseases Act; the Lead Based Paint Poisoning Prevention Act; the Clinical Laboratories Improvement Act of 1976; and the Mental Retardation Facilities and Community Mental Health Center Construction Act of 1963. The latter act authorized construction of mental retardation research centers and university-affiliated facilities to conduct basic research on mental retardation and to train professionals in the field of mental retardation. In addition, the Congress has specifically mandated the maternity and infant care, infant intensive care, and family planning projects, authorized under title V of the Social Security Act, to help reduce the incidence of mental retardation.

DEFINITION OF MENTAL RETARDATION

The American Association on Mental Deficiency defines mental retardation as significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested before age 18. Significant subaverage intellectual functioning means more than two standard deviations below normal on intelligence quotient tests (approximately 70 and below). The Association categorizes successive degrees of impairment as mild, moderate, severe, and profound. The range of intelligence quotients and HEW's estimate of the percentage of mentally retarded in each level follows.

Level of mental retardation	Intelligence quotient	Estimated percent of occurrence
Mild	52 to 67	89.0
Moderate	36 to 51	6.0
Severe	20 to 35	3.5
Profound	19 and below	1.5
		100.0

The Association defines behavior as the effectiveness or degree with which the individual meets the standards of personal independence and social responsibility expected of his age and cultural group. Therefore, persons with low intelligence quotient scores but who have sucessfully adapted are not considered retarded. Conversely, individuals who show poor adaption but normal intelligence are also not classified as retarded.

The more severe cases of retardation are likely to be associated with organic defects and tend to be spread evenly throughout the population. However, the mildly retarded are concentrated among low-income families.

CAUSES OF MENTAL RETARDATION

Many causes of mental retardation have been identified. Frequently, several factors and possible causes may coexist, interact, or overlap, making it difficult to identify a specific cause.

Following are some of the major causes of retardation.

Metabolic disorders

A child born with a metabolic disorder cannot convert certain foodstuffs into energy because he lacks a specific enzyme. These disorders are inherited from both parents as each parent passes one faulty gene to the unborn child. If untreated many metabolic disorders can produce mental retardation. Phenylketonuria (PKU) is one of the more commonly known of these disorders.

Prematurity and low birth weight

It is not conclusive that prematurity or low birth weight alone handicap an infant's intellectual and behavioral development. However, mental retardation occurs much more frequently in premature or low birth weight infants than among full-term or normal birth weight infants.

Malnutrition

Severe malnutrition, particularly during pregnancy and the first 6 months following birth, can substantially impair brain development. The effects of milder degrees of malnutrition are less clear-cut, but it is generally agreed that a good diet during pregnancy and infancy can help reduce the incidence of mental retardation by

--lessening the incidence of low birth weight;

--lessening the likelihood that toxic substances, which might harm the baby, will be in the mother's blood; and

--improving the mother's general health, enabling her to better cope with such possible hazards as infection or hemorrhage.

Chromosome abnormality

Chromosomes are the threadlike parts of human cells that carry hereditary traits. Normally, every cell in the body has 46 chromosomes. However, genetic errors can occur which may result in an individual having too many or too few chromosomes or in part of a chromosome breaking off and reattaching to another chromosome. For example, Down's syndrome, a major clinical cause of mental retardation, usually results from the presence of an extra chromosome.

Infections

Several infections, such as rubella (German measles), are hazardous for an unborn baby if contracted by the mother during pregnancy. Others, such as regular measles (rubeola), can cause mental retardation when contracted by young children. Other examples are: syphilis, mumps, and chicken pox.

Intoxication

Intoxication is poisoning produced by a drug, serum, or other toxic substance. Types of intoxication include lead poisoning and Rh blood incompatibility between mother and baby. Chronic alcoholism in the mother can also result in mentally retarded offspring.

Brain injury or disease

Injury can result from an accident involving the pregnant woman; injury during the birth process, such as forceps injury; or injury to the child after birth, such as an automobile accident or child abuse.

Brain damage can also occur from oxygen starvation as a result of breech delivery, twisting of the umbilical cord, or premature separation of the placenta.

Mental retardation can also be caused by brain disease, such as tuberous sclerosis, tumors, blood clots, or hemorrhage.

Environmental influence

In about three-fourths of the diagnosed cases of mental retardation, no organic cause can be identified. Adverse environmental conditions are considered a major cause of this kind of mental retardation, commonly called "sociocultural," "cultural-familial," or "retardation associated with psychosocial disadvantage."

Children with economically, socially, and educationally deprived backgrounds are at high risk. According to one expert, children born and reared in urban ghettos or impoverished rural areas are 15 times more likely to be diagnosed mentally retarded than children from middle-class, suburban environments.

Although there is still a great deal of debate about what actually causes this kind of retardation, a number of factors appear to be involved.

Physical factors (infection, nutrition, poisons, etc.) have not been ruled out as possible contributing causes of sociocultural retardation. Experiments have been conducted, however, in which children from poor environments were provided early developmental experiences. Such children usually achieved at least average intellectual performance. Many professionals, therefore, believe that early experiences are the most important factors in causing or preventing sociocultural retardation.

PURPOSE AND SCOPE OF REVIEW

We made our review to determine what has been done to prevent retardation and what can and should be done to reduce it.

We contacted headquarters and regional officials of the following HEW agencies and offices about their roles in prevention, any emphasis they had given to it, or assistance they had given to the States.

Office of Human Development:
- Office for Handicapped Individuals
- Office of Child Development
- Rehabilitation Services Administration
- Developmental Disabilities Office
- Staff of the President's Committee on Mental Retardation

Office of the Assistant Secretary for Health:
- Office of Population Affairs
- Division of Health Services and Prevention Operations
- Alcohol, Drug Abuse, and Mental Health Administration
- Center for Disease Control (CDC)
- Office of Child Health Affairs
- Health Resources Administration
- Health Services Administration
- National Institutes of Health

Health Care Financing Administration: 1/
- Medical Services Administration

Office of Education:
- Bureau of Education for the Handicapped

We visited the State departments of health and education in California, Georgia, and Missouri and other federally or State-supported activities to determine what programs they operated relating to retardation and what evaluation had been made of the programs' impact on prevention. We contacted private organizations, such as the National Foundation-March of Dimes, hospitals, and colleges, to determine their role in prevention of retardation, and read a great deal of literature on the subject. In particular we relied heavily upon National Association for Retarded Citizens publications to explain highly technical subjects in nontechnical terms.

1/On March 8, 1977, the Secretary of HEW announced the abolishment of the Social and Rehabilitation Service and the transfer of the Medical Services Administration to a new Health Care Financing Administration. Because the Social and Rehabilitation Service was the responsible agency during the period covered by our review we will use that name throughout this report.

Chapter 2 of this report describes some of the HEW programs and agencies which provide services to the retarded or relate to prevention of retardation. The remaining chapters focus on selected causes of mental retardation for which it appears that more intensive implementation of the techniques would result in reduced incidence. Neither the selection of specific causes nor the arrangement of chapters in this report are intended to stress the importance of any one cause or minimize the significance of other causes.

While we have concentrated in this report on actions that can be taken to prevent mental retardation with existing knowledge and technology, we recognize that research is needed and is ongoing into the causes and possible methods of preventing mental retardation.

In addition to HEW and the President's Committee on Mental Retardation, the States of California, Georgia, and Missouri were given an opportunity to comment on a draft of this report. Comments were received from Missouri officials and those comments have been considered in this report. PCMR agreed with our recommendations and advised us that they will be meeting with representatives of each of the Federal departments in order that each department may identify those programs they will initiate or expand in order to make significant contributions to reducing the incidence of mental retardation.

CHAPTER 2

IMPROVEMENTS NEEDED IN HEW ADMINISTRATION OF THE PREVENTION EFFORT

Despite the President's goal of reducing mental retardation by half by the end of the century, (1) no HEW agency has been made responsible for monitoring the implementation of the goal, coordinating efforts, clarifying agency roles and resource commitments, or measuring progress in meeting the goal; (2) the goal has not been designated an objective by those HEW agencies with prevention responsibilities; and (3) systems have not been established or methods developed to assess progress in achieving the goal.

FEDERAL INVOLVEMENT

In 1963 President Kennedy sent a special message to the Congress calling for national programs to combat mental retardation. Since then, Federal efforts aimed at preventing mental retardation have grown substantially. The Federal Government has (1) sponsored biomedical research; (2) provided funds to pay for clinical and laboratory services, construction, and training; (3) sponsored demonstration projects to stimulate States to commit resources to preventing retardation; and (4) funded grant-in-aid programs to help States provide preventive services.

HEW is the principal Federal department concerned with mental retardation. As far back as 1962, the President's Panel on Mental Retardation 1/ reported that HEW must assume major responsibility at the Federal level in areas of mental retardation. The panel also stated that HEW should serve as a resource to the other departments for whatever expert consultation is required.

At least seven HEW agencies administer programs that relate to prevention of mental retardation by providing funds for

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1/A panel appointed by the President on October 17, 1961, to prepare a national plan to combat mental retardation. The panel was dissolved following the publication of its report in October 1962.

--services to mothers, infants, and children, such as direct clinical care, medical services, and education;

--training of professionals;

--construction of research and training facilities; and

--research and demonstration projects.

These agencies are the Office of Human Development; Health Services Administration; Social and Rehabilitation Service (see footnote on p. 6); Office of Education; National Institutes of Health; Alcohol, Drug Abuse, and Mental Health Administration; and the Center for Disease Control. Some of the programs these agencies administer are discussed below.

Maternal and child health and crippled children's programs

Grants are made to States under these programs. The basic purposes of these programs are to (1) reduce infant mortality and otherwise promote the health of mothers and children and (2) locate, diagnose, treat, and provide followup care for children who suffer from crippling or handicapping illnesses. These programs, which are authorized under title V of the Social Security Act (42 U.S.C. 701), are the major means through which the Government provides (1) basic preventive maternal and child health services to persons in economically depressed areas and (2) services to crippled children.

To receive their maternal and child health and crippled children's funds the States must have a plan which includes a "program of projects" in maternity and infant care, intensive infant care, comprehensive health care for children and youth, dental health care for children, and family planning. Title V funds also support 166 mental retardation clinics, 20 biochemical and cytogenetic laboratories, and training programs at 21 university-affiliated facilities. 1/ The maternal and child health and crippled children's

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1/The university-affiliated facilities, which were constructed with Federal funds, are designed to provide comprehensive multidisciplinary training for specialists who will work with the mentally retarded and other developmentally disabled individuals.

programs combined were appropriated $282.9 million in fiscal year 1975 and $319.4 million in fiscal year 1976.

Developmental disabilities program

Formula grants are provided to States under the Developmentally Disabled Assistance and Bill of Rights Act (42 U.S.C. 6001) for planning, administering, and evaluating programs; constructing facilities; and providing services for the developmentally disabled, primarily the mentally retarded. The program also provides administrative support funds to university-affiliated facilities. This program was appropriated $55.6 million in fiscal year 1976.

Family planning programs

Family planning programs are authorized under many separate laws having different program objectives. Health program financing for family planning services are authorized under title V of the Social Security Act (included under maternal and child health programs) and title X of the Public Health Service Act. Other HEW family planning activities are funded under titles XIX (Medicaid) and XX of the Social Security Act. HEW expenditures for family planning programs totaled an estimated $167 million in fiscal year 1975, including an estimated $35 million expended under title V. Family planning helps to prevent mental retardation by promoting optimal child spacing and helping to prevent unwanted pregnancies.

Mental retardation research centers

Twelve mental retardation research centers were established to investigate mental retardation problems and related aspects of human development and to provide training opportunities for research specialists. The research centers receive funding from several Federal, State, and private sources. The National Institute of Child Health and Human Development provides administrative support for the centers.

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)

The Social Security Amendments of 1967 required EPSDT to be implemented in every State that had a Medicaid program. The purpose of health screening is to identify children with

previously unrecognized health problems as early as possible. The EPSDT program is designed to periodically survey children to be sure there are no hidden problems. The States reported expenditures of $46.3 million in fiscal year 1976 for screening. This figure does not include treatment costs.

Head Start

The Head Start program was established in 1965 to provide health, educational, nutritional, social, and other services primarily to economically disadvantaged preschool children, their families, and their communities. The program is currently administered by the Office of Child Development within the Office of Human Development. Head Start program officials stated they believe the program helps reduce the effects of mental retardation although that is not a specific Head Start goal. The Head Start program had a $461.5 million appropriation in fiscal year 1976.

Disease prevention and control

CDC operates several programs which relate to mental retardation prevention, including lead poisoning screening projects, project grants to States for immunization programs, and surveillance of incidence and immunity levels of infectious diseases, Rh blood disease, and congenital malformations. CDC was appropriated $3.5 million for lead screening and $4.96 million for immunizations in fiscal year 1976 compared to $9 million and $6.2 million, respectively, in fiscal year 1975.

Programs operated by other departments

Other Federal departments also have programs which relate to preventing mental retardation. These include the Department of Agriculture's nutrition programs and the Department of Housing and Urban Development's lead-based paint prevention programs.

RESPONSIBILITY FOR IMPLEMENTING, MONITORING, OR COORDINATING A NATIONAL PREVENTION STRATEGY HAS NOT BEEN FIXED

Although some HEW organizations have major responsibilities for coordinating or operating mental retardation activities or programs, including the President's Committee

on Mental Retardation 1/ and the Office for Handicapped Individuals, none has overall responsibility for developing a prevention strategy, determining and implementing efforts needed to accomplish the President's goal, or defining the responsibilities of agencies and programs that do or could have an impact on the goal. In addition, agencies that have major responsibilities for improving child health and preventing childhood disabilities, primarily the Bureau of Community Health Services, Health Services Administration, have neither developed a strategy for, nor established methods of, measuring progress in reducing its incidence.

President's Committee on Mental Retardation

PCMR was established in 1966 to (1) assist the President in evaluating the national effort to combat mental retardation, coordinate Federal activities, provide liaison between Federal and other public and private agencies, and educate the public on how to reduce the incidence of mental retardation and ameliorate its effects and (2) mobilize professional and general public support for mental retardation activities. Its staff is administratively located in HEW's Office of Human Development.

In 1971 President Nixon directed Federal agencies to put their full support behind PCMR to help reduce the incidence of mental retardation and directed all executive departments and agencies to evaluate their programs as the first step of a coordinated national effort.

PCMR's responsibilities were expanded by Executive Order 11776 in March 1974 to include identifying the potential of various Federal programs for achieving the Presidential goals in mental retardation, including prevention. This Executive order also required Federal agencies to designate mental retardation liaisons with PCMR.

PCMR has promoted public awareness of the needs of the mentally retarded and identified problems needing attention to help combat mental retardation and actions which could

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1/PCMR is not technically an HEW organization. However, because the Committee's staff is administratively located in HEW and because of the close ties it has with HEW, we included the Committee under this section.

help solve or alleviate many of the problems confronting the retarded. According to PCMR, its accomplishments have included:

--Being the catalyst in urging the President to (1) make prevention of mental retardation a national goal and (2) make statements on the need for immunizations and on lead poisoning prevention.

--Issuing several publications relating to the prevention of mental retardation.

--Sponsoring several symposiums, workshops, and meetings on the problems of mental retardation.

--Identifying 91 programs in 22 Federal departments and agencies that affect the mentally retarded.

--Identifying actions that could be taken by various Federal agencies to help reduce the incidence of mental retardation.

PCMR, however, has not been given, nor assumed, responsibility for directing Federal efforts to prevent retardation nor has it been given the responsibility to initiate, implement, or coordinate programs or to assess the progress of HEW agencies in meeting the Presidential goal.

Although, as mentioned above, PCMR does have certain responsibilities relating to the achievement of the Presidential goal, its responsibilities are not specific and PCMR does not have the resources to fulfill its Presidential mandate. This may also be due, in part, to a May 1974 agreement between PCMR and the Office for the Handicapped (now Office for Handicapped Individuals) which stated that the Office for the Handicapped would take responsibility for conducting mental retardation activities within HEW and PCMR would coordinate the activities of departments and agencies outside of HEW. The agreement did not specify whether this responsibility included prevention of mental retardation. Because the activities of agencies outside HEW primarily involve services to the retarded rather than prevention of retardation, we did not determine the extent to which PCMR carried out this agreement.

Office for Handicapped Individuals

The Secretary of HEW established an Office of Mental Retardation Coordination in 1972 to coordinate the Department's programs and activities affecting the mentally retarded, including prevention activities. The Office's reponsibilities were changed in February 1974 by the Rehabilitation Act Amendments of 1974 and its name was changed to Office for the Handicapped; the name was later changed to Office for Handicapped Individuals.

As a result of these changes, prevention of mental retardation ceased to be an Office objective. As its name suggests the Office of Handicapped Individuals provides and coordinates services to individuals already identified as handicapped. The Office does not consider prevention of handicapping conditions to be a part of its mandate. An Office official said that the Office had neither initiated or implemented any new programs nor coordinated already existing programs to prevent retardation; nor had it been asked to do so.

Bureau of Community Health Services

The Bureau of Community Health Services, Health Services Administration, was established to help communities find the best ways of meeting their health needs. Several Bureau programs help prevent mental retardation, including maternal and child health programs, mental retardation clinics, cytogenetic and biochemical laboratories, family planning, and financial support to university-affiliated facilities. These programs are described on pages 9 and 10.

The Bureau's Deputy Director for Maternal and Child Health Program Services stated that the Bureau, more than any other HEW agency, should be responsible for implementing the President's goal. Moreover, its maternal and child health special projects (maternity and infant care, intensive care, and family planning) are specifically mandated by the Congress to help reduce the incidence of mental retardation. Nevertheless, the Bureau neither developed a strategy to accomplish the goal nor monitored progress toward achieving it.

A Bureau official told us that, although a specific objective to prevent mental retardation had not been established, mental retardation was an integral part of maternal and child health services. In addition, he stated that the Bureau had emphasized prevention of mental retardation by the

Congress earmarking of funds (the earmarking is no longer done but the Bureau has agreed to reserve the funds for that purpose) for special mental retardation projects such as mental retardation clinics and biochemical and cytogenetic laboratories. However, data is lacking on the impact of these programs on the prevention of mental retardation.

The following reasons were given as to why the prevention of mental retardation had not been clearly stated as a specific objective for maternal and child health programs.

--The maternal and child health programs have been reorganized three times under different agencies, not all of which emphasized mental retardation programs.

--The grant authority for maternal and child health programs has been decentralized to the regions, thus reducing headquarters involvement.

--Sizable cuts in staff have precluded monitoring or focusing on this area.

--The lack of an objective at the departmental level.

THE PRESIDENT'S GOAL HAS NOT BEEN ESTABLISHED AS AN HEW OBJECTIVE

Although HEW is the primary Federal agency responsible for preventing mental retardation and providing support to the retarded, neither it nor its constituent agencies have established the President's goal of reducing the incidence of retardation by half by the end of the century as a departmental or agency objective.

HEW implemented a management-by-objective system in 1969. The system is a part of the Federal management-by-objective system administered by the Office of Management and Budget. Briefly, HEW's planning incorporates the following components:

--Issue analysis and policy development.

--Forward plans, which set the Department's long term direction (2 to 6 years).

--Operational plans, which are immediate steps the Department must take to accomplish long-range goals.

Our review of the Secretary's annual planning guidance memorandums issued from 1972-75 showed that prevention of mental retardation was not specifically identified as an issue to be addressed in HEW's planning system. PCMR officials told us that for fiscal year 1977, HEW is considering adding prevention as an operational objective under the management-by-objective system using the deinstitutionalization objective as a model.

PCMR was designated lead agency in developing the deinstitutionalization strategy. In carrying out this objective, PCMR set up five task forces, one of which was concerned with the prevention of institutionalization. The chairman of that task force told us that it will address preventing mental retardation as one way of preventing institutionalization. 1/ However, he did not expect to develop a specific strategy for preventing mental retardation.

Although prevention of mental retardation had not been designated an objective by any of the agencies we contacted, some agencies had related objectives. For example, the Health Services Administration implemented a child health objective beginning in fiscal year 1975 which included prevention aspects, such as:

--Improving the health of children by increasing accessibility to health care and the scope of services.

--A coordinated HEW effort to implement the Early and Periodic Screening, Diagnosis, and Treatment program.

--Maintenance of current immunity levels among children up to age 9 during a period when grant resources are being reduced. We were told, however, that this portion was not included in the objective for fiscal year 1976 because of the priority given the swine flu vaccine.

1/Efforts to provide services to mentally disabled persons in communities rather than institutions was the subject of our report "Returning the Mentally Disabled to the Community: Government Needs to Do More" (HRD-76-152, Jan. 7, 1977).

In June 1975, HEW's Public Health Service reported in its Forward Plan for Health, fiscal years 1977-81, that the child health strategy will focus on reducing infant mortality and low birth weight by giving special attention to genetic factors and maternal health services, including family planning. Also, immunization targeted to low-income families and cooperative activities with the Medical Services Administration in conducting the Early and Periodic Screening, Diagnosis, and Treatment program are highlighted.

In its Forward Plan for Health, fiscal years 1978-82, the Public Health Service outlined five of its objectives, including implementation of an aggressive prevention strategy. This objective included improving the effectiveness of prevention activities in alcoholism, drug abuse, and mental illness--mental retardation was not mentioned.

However, another part of the objective did state that particular priority would be given to (1) making amniocentesis (see p. 45) generally available to women over age 35, (2) decreasing the rate and adverse consequences of adolescent pregnancies, (3) increasing immunization levels of children, and (4) beginning a program of assisting States to develop child health care systems. All of these could affect prevention of mental retardation.

We discussed the President's goal and the management-by-objective system with officials of the Management Division of the Office of Management and Budget. They said that the Office of Management and Budget had not taken any specific action to implement the President's 1971 directive because HEW had not asked for the Office's assistance.

LACK OF DATA TO MEASURE PROGRESS IN MEETING THE GOAL

HEW has not developed a system to collect data on the incidence of retardation. In addition, no method has been developed to collect information on a special-study basis nor has an organization been assigned responsibility for developing such data.

Incidence and prevalence data can be used to determine the extent and distribution of a condition and to measure progress in reducing it. Incidence of retardation refers to the frequency of occurrence of new cases of mental retardation in a population during a designated period. Prevalance refers to the proportion of persons in a population who

are considered mentally retarded at a given time. The incidence of mental retardation ultimately determines its prevalence.

In 1962 the President's Panel on Mental Retardation recommended that a system for gathering information on the incidence and prevalence of mental retardation be developed. In November 1971 the President directed the Bureau of the Census to take steps to develop more complete data on the extent of mental retardation. We were informed by PCMR and Bureau of the Census officials that Census had taken no action to develop such data primarily because:

--Census would have no method before the 1980 census for obtaining an accurate assessment short of knocking on every door and asking how many retarded individuals lived there.

--Even if a method could be developed, Census did not have sufficient funds to conduct such a survey.

In a 1976 report to the President, PCMR cited some of the difficulties in trying to determine the incidence and prevalence of mental retardation, including:

--The cause in each case of mental retardation cannot be identified so incidence cannot be determined at its source.

--In only a few cases can mental retardation be determined at birth.

--Children classified socioculturally retarded do not begin to show deficits in functioning until after they begin school.

--There is no assurance that a person identified as being retarded may not at some time cease to be so regarded.

Without good incidence data it is difficult to develop information on the prevalence of mental retardation. PCMR pointed out that the incidence of the more severe forms of retardation can be determined with a fair degree of accuracy because the individuals are obviously retarded and the diagnosis can usually be confirmed medically. But when the mildly retarded are added, the accuracy is questionable.

For example, for many years the prevalence of mental retardation was estimated at 3 percent of the population. This estimate, however, is now disputed. One authority believes that, while it may be correct to say that about 3 percent of all children born will sometime be diagnosed as retarded, it is incorrect to conclude that on any given date 3 percent of the population could be classified as retarded. He placed the latter figure at about 1 percent and attributes the difference in part to persons who are identified as retarded during their school years, but escape this labeling as adults.

The widely quoted 3-percent figure is affected by many factors including

--changes in definition of mental retardation,

--ways used to identify mildly retarded individuals, and

--confusion regarding what constitutes sociocultural retardation.

In addition, significant differences in prevalence occur among different regions, ethnic groups, and income groups.

In a March 1976 report to the President, PCMR recommended that the Federal Government create a national information system on mental retardation through which its departments and the States could get prompt and reliable data on which to base their planning. We discussed with PCMR the difficulty of developing an information system that would assess progress in preventing mental retardation in light of the difficulties of accurately measuring incidence and prevalence. The Executive Director told us that, although data on the incidence of retardation was not available, various other indexes could be used to measure progress, such as reductions in the number of children in special education classes or institutions, reductions in the number of cases of retardation due to specific causes for which incidence is known, and reductions in the incidence of known causes of retardation such as prematurity and genetic disorders where the incidence of retardation is not as certain.

Officials of the Mental Retardation Research Center at the University of California, Los Angeles, said that progress in prevention could also be measured by using data generated by programs involved in early screening, such as EPSDT, and by developing a tracking system to monitor services provided to the retarded. Eventually, reductions in the services provided would indicate reductions in incidence.

PCMR's Executive Director told us that some agencies, particularly the Bureau of Community Health Services and the National Institute of Child Health and Human Development, have been working on ways to assess the impact of specific programs or projects on reducing the incidence of retardation. However, no agency within HEW has been specifically made responsible for studying possible methods of measuring progress in meeting the Presidential goal.

CONCLUSIONS

If the incidence of mental retardation is to be reduced to the maximum extent possible a specific group within HEW must be made responsible for implementing and monitoring a national prevention strategy, clarifying agency roles, and determining which and how HEW programs can best assist in the effort. The responsibilities of this organization should include coordinating the mental retardation prevention efforts of the various HEW programs and developing a method to measure the progress being made.

If the Presidential goal is to be meaningful, a method of compiling comprehensive data on the incidence and prevalence of mental retardation, on either a continuing or special-study basis, should be developed. This would be in addition to the need for an operational objective which would establish responsibilities and coordination and would determine what actions the various HEW programs could take to assist in the prevention effort.

RECOMMENDATIONS

We recommend that the Secretary of HEW:

--Designate a focal point within HEW to implement a national prevention strategy, monitor and coordinate the efforts of the various HEW agencies and offices, and develop a method of determining the progress being made in reaching the goal.

--Designate prevention of mental retardation an objective in HEW's operational planning system.

AGENCY COMMENTS AND OUR EVALUATION

HEW agreed with our recommendation to designate a focal point in HEW for the mental retardation prevention effort. The

Office of the Assistant Secretary for Health will be the focal point. Specific responsibility will be designated by the incoming Assistant Secretary for Health.

As to our recommendation that prevention of mental retardation be designated as an objective in HEW's operational planning system, HEW advised us that they would consider including it as an objective if the operational planning system is continued. Whether the departmental system is continued or not, the relevant issues will be monitored by the agency tracking system.

We believe the HEW comments are responsive to our recommendations. Our recommendation that prevention of mental retardation be established as an objective in the operational planning system was made as one possible method to monitor implementation of the Presidential objective by the various agencies in HEW. Other methods which would accomplish this would also be responsive to the intent of our recommendation.

CHAPTER 3

EXPANDING NEWBORN SCREENING FOR METABOLIC DISORDERS

Mental retardation caused by inherited metabolic disorders 1/ can often be prevented if the afflicted infant is treated shortly after birth.

As of 1975 almost all States had programs for testing a sample of blood of newborn infants to detect phenylketonuria, one of the most widely known metabolic disorders. However, improvements are needed in many of these programs to effectively reach all infants. Also, only a limited number of States were testing for other treatable metabolic disorders which can be identified from the same blood sample.

Metabolic disorders are not common; however, our analysis of the estimated costs and benefits of PKU screening showed that the monetary savings that result from avoided costs of caring for retarded individuals significantly exceed the cost of screening all newborn infants and treating the affected individuals. Also, by using automated laboratory methods, tests for other disorders can be made on the blood sample drawn for PKU testing at little or no additional cost (when done on a large number of blood samples), thereby preventing even more cases of mental retardation and realizing greater savings.

Federal maternal and child health funds support newborn screening programs in many States. However, although HEW has encouraged the States to improve their screening programs, the basic responsibility lies with the States. Therefore, some programs are more comprehensive and effective than others.

BACKGROUND

About 200 metabolic disorders have been discovered although not all result in mental retardation. Many are

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1/We recognize that metabolic disorders and chromosome abnormalities, which are discussed in chapter 5, and their preventive techniques are not mutually exclusive. However, we separated them because the diagnostic techniques and nature of the diseases are generally quite distinct.

treatable by special diet or dietary supplements, but for treatment to be successful in preventing mental and physical damage, it must be started soon after birth.

One of the most widely known metabolic disorders associated with mental retardation is PKU. The child with PKU cannot produce the enzyme which metabolizes a particular protein in food. The child appears healthy during the first few months of life and will show signs of the disease only in blood and urine. If the disease is not discovered and dietary treatment begun shortly after birth (within 4 to 6 weeks according to one expert), the child will likely be retarded; the longer treatment is delayed, the more severe the retardation.

Other treatable metabolic disorders which can cause retardation include homocystinuria, galactosemia, maple syrup urine disease, tyrosinosis, histidinemia, and hypothyroidism.1/ Homocystinuria, like PKU, should be identified and treatment started within 4 to 6 weeks after birth. Similarly, if treatment for hypothyroidism is to be most effective, it should start within 3 months after birth. Galactosemia, maple syrup urine disease, and tyrosinosis are more acute and treatment should be started as soon as possible after birth; a delay of a week can be devastating. For histidinemia, the exact link to retardation and the recommended course of treatment are not as clearly known as they are for the others.

Using available reported data and estimates by genetic service providers, we estimated that about 1,100 babies are born each year afflicted with one of the seven disorders named above. (See p. 30.)

AVAILABLE SCREENING PROGRAMS

Screening for early detection of metabolic disorders has been conducted for only about 15 years and has been confined, until recently, largely to PKU.

As of 1975, 48 States had PKU screening programs. In almost every State testing was mandatory under State law and was regulated by the State's department of health. Most State laws require that all newborn infants be tested

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1/Hypothyroidism is technically an endocrine disorder but we have included it among metabolic disorders because of similarity in detection and treatment.

unless the parents object on religious grounds; some do not require the test if there is general parental objection. Even in those few States and jurisdictions that do not have mandatory screening programs, most infants are tested.

In general, most States place the responsibility for insuring that tests are performed on the delivering physician, the administrative head of the hospital, or, if the newborn was not delivered by a physician, the mother, nurse, midwife, or other person assisting in the delivery. Most samples are analyzed as a public service by State health department laboratories.

The most widely used PKU screening test is the Guthrie Bacterial Inhibition Assay. Maternal and child health funds were used to carry out field trials in 32 States to establish the accuracy and efficiency of this procedure. The Guthrie test entails collecting a few drops of blood on a filter paper which is sent to a laboratory for analysis. Babies who appear to have a disorder based on the Guthrie test are followed up with confirmatory diagnostic procedures.

The Guthrie inhibition assays can also be used to screen for maple syrup urine disease, tyrosinosis, homocystinuria, and histidinemia. According to the developer of the test, with automation all these tests can be done simultaneously at no more cost than PKU alone unautomated. Also, with automation, the same single blood sample can be used to test for galactosemia and hypothyroidism at little additional cost. However, as discussed on page 26, only a limited number of States are testing for these other disorders.

COVERAGE FOR PKU APPEARS INCOMPLETE

The National Academy of Sciences has reported that about 90 percent of the babies born in the United States are tested for PKU. However, coverage in some areas appears less than optimal.1/ We could not, however, precisely determine whether the problem in a specific State was inadequate coverage or incomplete reporting.

1/ The Director of the Metobolic Disorders Section, Genetics Division, Children's Hospital, Los Angeles, advised us that ideally all infants should be screened for PKU and that 90 percent would be the minimally acceptable level of coverage.

In 1975 a member of the Prevention and Public Health Committee of the National Association for Retarded Citizens sent a questionnaire to health officials in each State. Only 15 States have statistics showing that their screening programs were reaching 90 percent or more of the babies born; 5 States were reaching 80 to 90 percent, 2 were reaching 70 to 80 percent, and 4 were reaching only 60 to 70 percent.

In five other States, reported data showed coverages ranging from 53 to 85 percent. However, officials in these States indicated that the records were incomplete and estimated that from 87 to 100 percent of the babies born were screened. Similarly, in two other States, statistics showed screenings of 59 and 87 percent of the babies born. Officials in these States indicated these numbers were incomplete but did not know the actual coverage.

In seven other States, no records were available on the extent of screening, but State officials estimated that 95 to 100 percent of the babies born were screened; in another seven States, no estimate of screening coverage was made. Two States had no program and one State did not respond.

Of the States we reviewed, California reported that 99 percent of all newborns were screened for PKU, but coverage in the other States was lower. In Georgia, for example, about 67,900 newborns were reported as having been screened for PKU in fiscal year 1974; this was only about 79 percent of the approximately 86,000 babies born in that period. About 42,000 PKU newborn screenings were reported by Missouri in 1974, or about 60 percent of the babies born that year. The Director of the Missouri Bureau of Maternal and Child Health estimated that 85 percent of the infants born in the State were being screened for PKU but, in his opinion, many of the screenings are not reported. However, the Director of the Division of Medical Genetics at Washington University School of Medicine estimated that as many as 30 percent of the newborns in Missouri are not being screened.

No documentation was available in the States we reviewed on the incidence of PKU in infants missed during the screening process. However, experts told us that

--even with coverage as low as 70 to 80 percent in Missouri and Georgia, few, if any, cases of PKU would be missed each year;

--it would be very hard to locate such cases among the numerous facilities providing care for the retarded;

--it is likely that cases in remote rural or mountainous areas, those most likely to be missed by newborn screening, will not be identified as PKU;

--cases missed by screening often will not be recognized by physicians because PKU will not show up in routine blood or urine testing and must be specifically tested for; and

--even those placed in institutions for the retarded would probably not be diagnosed as having PKU because of the absence of routine testing for PKU by such facilities and the inability of the staff to recognize its symptoms.

Officials at one mental retardation clinic in Missouri said they were aware of only one case that had slipped through the screening program. They said cases were probably being missed, but were not showing up at the clinic.

STATES GENERALLY DON'T SCREEN FOR OTHER DISORDERS

Although almost all States have newborn screening programs for PKU, at the time of our review, screening for other metabolic disorders was done routinely by only eight States.

Disorder	Number of States screening (note a)
Galactosemia	8
Homocystinuria	7
Maple syrup urine disease	6
Tyrosinosis	4
Hypothyroidism	4
Histidinemia	3

a/ Three of these States (Oregon, Montana, and Alaska) participate in a single regionalized screening program.

Of the States we reviewed, Georgia and Missouri had mandatory PKU screening programs, but did not routinely screen for other metabolic disorders. In Georgia other screening has been done on a limited basis. For example, in 1975 as a special project of Emory University, 650 infants were screened for maple syrup urine disease, galactosemia, and homocystinuria.

California passed an expanded newborn screening law in 1975 which allows the department of health to require that tests be done for other metabolic disorders in addition to PKU. The law was to become effective July 1, 1976, but controversy over which diseases should be tested and whether private or State laboratories should do the testing has delayed implementation. State health officials expect the program to start about July 1977.

One California health official commented that he was not convinced that testing for some of the disorders had been proven beneficial enough to warrant investing State resources. Similar arguments have been expressed by other physicians and this hesitation appears to be one reason why screening has not been more widespread.

Mass screening programs have not been enthusiastically supported by the medical profession. In a 1974 National Academy of Sciences survey of physicians, nearly three-fourths of the respondents believed that screening for particular disorders should be encouraged, but over half were opposed to mandatory screening. Only about one-fourth of the 1,000 doctors questioned believed that the benefits of PKU screening outweighed the costs; about 25 percent believed that screening was not warranted; and 50 percent had no opinion.

The Chairman of the Academy's Committee for the Study of Inborn Errors of Metabolism attributed this hesitation to a lack of knowledge. Most of the physicians questioned had no genetics course in medical school. In general, they tended to underestimate the incidence of genetic diseases, the importance of identifying them, and the possibilities for treatment. Few acknowledged seeing such problems and few read about them. Most physicians believed that there should be more emphasis on genetics in primary medical education, as well as continuing education at higher levels.

Dr. Robert Guthrie, the developer of the most widely used screening test, reports that another reason why testing has not been expanded in more States to include other metabolic disorders is that screening programs have primarily been restricted to within State boundaries and many State populations are too small to justify testing for the rarer disorders. He has reported that to get full value from automated screening it must be done on a large scale--a minimum of 25,000 births a year. Therefore, he argues that consolidation of screening is needed (1) within large States where screening is fragmented into many programs, each too small to make multiple testing practical, and (2) between or among States where populations are too small to warrant multiple screening within each State. Bureau of Community Health Services officials agree that consolidation or regionalization of screening programs is needed.

The National Academy of Sciences reported in 1975 that regionalization has been the object of considerable interest as a means of reducing the number of laboratories carrying out tests, facilitating quality control, and reducing costs. In a 1975 survey of State laboratories conducted by the National Association for Retarded Citizens, 36 of the 42 respondents who answered the question, including the 3 States in our review, indicated that they are considering or would consider cooperating with neighboring States in a regional screening program. Oregon already operates a regional newborn metabolic screening program which serves Oregon, Montana, and Alaska. Idaho is also contemplating joining the program. Bureau of Community Health Services officials told us that Massachusetts started providing screening services to other New England States subsequent to our fieldwork.

SCREENING AND TREATMENT CAN BE COST EFFECTIVE

Using information and opinions obtained from several experts in the fields of metabolic disorders and newborn screening, including Dr. Guthrie, we estimate that PKU screening, under a well-organized automated system, and lifetime treatment of afflicted individuals would cost about $3.3 million a year. However, such screening could prevent about 270 cases of mental retardation and avoid $189 million a year in costs of providing care and services for individuals who, without

screening and treatment, would be mentally retarded.1/ Discounted to present value, using a 10-percent interest rate, these figures would be $2.9 million and $35.9 million, respectively. We also estimate that adding screening and treatment of the other six disorders would raise costs to about $18.5 million ($9 million discounted to present value) a year, but could prevent as many as 305 cases of mental retardation each year and increase the savings of lifetime care costs to about $437 million ($78.5 million discounted to present value).

Although the concept of relating benefits to costs is simple, its actual application is complex and difficult. The major benefit usually cited in preventing retardation is the avoided costs of caring for the retarded individual. Another factor that should be considered, however, is the benefit to society of having an individual who is not retarded but would have been without the program. These benefits accrue continuously over his or her lifetime, taking different forms and affecting different sectors of society such as: reduced unemployment, reduced welfare payments, increased job productivity, and increased tax revenue. We did not analyze the latter benefits because of the inherent difficulties in measuring their monetary value. For the same reason, we did not consider the savings in human suffering associated with avoiding retardation. We recognize, therefore, that the benefits of screening are understated in our analysis.

The details of the analysis are shown on the following page.

1/As noted above, newborn screening programs for PKU are already in operation in most States. Therefore, much of the costs and savings shown are already being realized.

Disorder	Projected annual occurrence (note a)	Estimated cost of screening and treatment: Screening (note b)	Lifetime treatment cost: Undiscounted estimate	Lifetime treatment cost: Present value (note d)	Estimated savings of lifetime care costs: Estimated percentage retarded in absence of screening	Number retarded (note e)	Projected lifetime cost of care: Undiscounted estimate	Projected lifetime cost of care: Present value
Phenylketonuria	273	$2,363,000	$ 983,000	$ 749,000	99	270	$189,254,000	$35,939,000
Maple syrup urine disease	15	473,000	3,750,000	781,000	5	1	618,000	320,000
Homocystinuria	14	473,000	1,092,000	176,000	75	11	4,177,000	1,378,000
Galactosemia	42	473,000	(c)	(c)	34	14	6,134,000	2,486,000
Tyrosinosis	10	473,000	1,500,000	495,000	5	1	528,000	249,000
Histidinemia	131	473,000	(c)	(c)	10	13	10,695,000	1,724,000
Hypothyroidism	630	1,575,000	4,914,000	792,000	42	265	225,779,000	36,398,000
Total cost for screening		$6,303,000	6,303,000	6,016,000				
Total cost of screening and treatment			$18,542,000	$9,009,000				
Total lifetime care cost							$437,185,000	$78,494,000

Notes: a/Computed by dividing 1974 births (rounded to 3.15 million) by incidence estimates obtained from the National Academy of Sciences and professionals in the field of metabolic disorders.

b/Based on estimated costs of screening using centralized automated laboratories. Allowance for sample collection is included in cost of PKU screening. All others represent only incremental cost to add them to PKU screening.

c/Treatment is not considered to incur significant costs above and beyond routine health care.

d/Costs were discounted at an annual rate of 10 percent.

e/Column 2 times column 6.

Several things must be pointed out regarding our analysis. First, the table is only a gross estimate because costs of treatment, length and course of treatment, anticipated outcome, or costs of care could vary significantly in each case. Therefore, the information is presented primarily to show the general advantages of prevention, not as a definitive analysis of costs and savings.

In computing the projected cost of lifetime care we used unit costs for services reported in a 1974-75 study of the cost of long term developmental disabilities care prepared by an HEW contractor. These figures ranged from $11,562 to $14,014 a year 1/ depending upon the severity of retardation and reflect a principal conclusion of that report that, given the same level of service, the costs of care are similar whether an individual resides in a community or in an institutional setting. 2/

Also, it should be noted that, although the cost of screening and treatment for tyrosinosis and maple syrup urine disease seems to be much higher than the lifetime cost of care if the diseases are not treated, this is because about 95 percent of the children born with these diseases will die within 3 years after birth if not treated. Similarly, it is estimated that 66 percent of those with galactosemia would die by age 3 without treatment. Based on these percentages an estimated 51 children would die annually from these conditions. We have not attempted to place a value on the loss of human life.

1/The costs cited were costs in California. According to a 1974 study by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, the median of the annual per-resident costs reported by 176 public residential facilities throughout the country was about $9,500.

2/We have reviewed other studies which indicate that community care costs might be lower than institutional care costs. We recognize that the question is subject to much debate. We are using this study because it provided current actual costs developed by tracing and recording services received by retarded individuals in community care facilities compared to institutional costs.

ABSENCE OF HEW DIRECTION

Although HEW has been supportive of State efforts to improve genetic screening programs, it has not evaluated the States' screening programs to determine which State programs appear to be the most comprehensive and effective or to identify where improvements could be made. Also, HEW has not aggressively encouraged States to adopt automated screening techniques, to expand screening to include metabolic disorders in addition to PKU, or to participate with other States in establishing regionalized screening programs.

HEW has funded studies of various screening techniques, and HEW funds support newborn screening programs in many States. For example, in California the newborn screening program is administered by the State Bureau of Maternal and Child Health which receives Federal monies for its administrative operations in the form of formula grants under title V of the Social Security Act. Similarly, the Missouri Bureau of Maternal and Child Health, which receives title V funds, oversees the screening in that State. The Missouri Bureau of Laboratory Services, which does most of the State's PKU tests, also receives Federal financial support.

An HEW official stated that in the absence of Federal law the Federal Government cannot tell States how their screening programs should be organized or what diseases should be screened. He pointed out that this is a matter of State discretion and is usually covered by State law.

However, the National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act (42 U.S.C. 300b) enacted April 22, 1976, could be used to establish or encourage screening for other disorders. The purpose of this act is to establish a national program to provide for basic and applied research, research training, testing, counseling, and information and education programs with respect to genetic diseases, including sickle cell anemia, Cooley's anemia, Tay-Sachs disease, cystic fibrosis, dysautonomia, hemophilia, retinitis pigmentosa, Huntington's chorea, and muscular dystrophy. The metabolic disorders discussed in this chapter are not required to be included in the program developed under this legislation. However, the legislation does permit inclusion of genetic disorders in addition to those specified.

As discussed on pages 24 to 26 many State screening programs appear to be less than effective in screening all newborns. To the extent that children are born with these diseases and are not identified and treated--Federal, State, and local governments must provide treatment and care for those who became retarded. In addition, there is the unnecessary waste of lives and human suffering. Federal programs, such as Supplemental Security Income, Medicaid, and other programs of the Social and Rehabilitation Service are especially affected; they must provide lifetime support or rehabilitation to individuals whose retardation might have been prevented.

CONCLUSIONS

Newborn screening for metabolic disorders and treatment of the cases identified can help prevent mental retardation, reduce human suffering, save lives, and avoid substantial costs of lifetime care for retarded persons. More can be done to improve and expand newborn screening programs. There has been an absence of aggressive Federal direction in the design, organization, or operation of newborn screening programs. The Federal Government stands to benefit directly from aggressive, comprehensive efforts by avoiding costs to various HEW programs for the care, treatment, and rehabilitation of persons who, without screening and treatment, would become retarded. Since HEW is currently developing regulations and guidelines for implementing the National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act, we believe that consideration should be given to using that legislation as a vehicle to implement the following recommendations.

RECOMMENDATIONS

We recommend that the Secretary of HEW help improve newborn screening by:

--Evaluating State screening programs to identify those which are not effective and provide them with necessary assistance.

--Encouraging and supporting expansion of newborn screening to include treatable metabolic disorders in addition to PKU.

--Encouraging and assisting States to cooperate to establish cost-effective regionalized metabolic screening programs.

AGENCY COMMENTS AND OUR EVALUATION

HEW agreed with our recommendations and pointed out several actions it was taking to implement the recommendations including addressing the need for newborn screening in its implementation plan for the National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act.

We believe the HEW actions are responsive to our recommendations and should result in considerable improvement in the coverage and cost effectiveness of infant screening programs for metabolic disorders.

CHAPTER 4

IMPROVING PRENATAL CARE TO REDUCE PREMATURITY AND LOW BIRTH WEIGHT

Comprehensive prenatal care can help prevent low birth weight and prematurity, thereby reducing the incidence of mental retardation. However, many women receive no prenatal care or do not obtain prenatal care until very late in their pregnancy.

HEW supports State prenatal care programs through title V of the Social Security Act. Health officials in each State we visited said the need for additional prenatal care was a significant health problem. However, in these States, the extent of the need for prenatal care, the location of those areas most in need, and the impact prenatal care programs have on reducing mental retardation have not been sufficiently analyzed.

In addition, HEW has not evaluated the State programs to assess their impact on the population served or to insure that resources are being applied most effectively.

INADEQUATE PRENATAL CARE IS LINKED TO PREMATURITY AND MENTAL RETARDATION

Many authorities believe that mental retardation caused by organic factors is best prevented by continuous, comprehensive, high quality prenatal care. Comprehensive prenatal care allows the physician to:

--Detect and manage chronic disease in the mother, such as diabetes, thyroid deficiency, PKU, etc.

--Detect and treat infections and be alert for exposure to viral disease such as rubella.

--Use prenatal fetal diagnosis to detect various genetic disorders.

--Monitor the course of Rh blood type incompatibility.

--Detect and treat poisoning and help prevent the use of harmful substances during pregnancy. Chronic alcoholism or drug addiction are of particular concern as potential causes of fetal damage.

--Encourage optimal maternal nutrition.

--Lessen the chances of a premature birth.

More extensive treatment is given elsewhere in this report to reducing mental retardation by increased preventive measures in infections, genetics, Rh disease, and lead poisoning. With regard to nutrition, all the programs we visited which provided prenatal care either included nutrition education and counseling or were affiliated with other nutrition programs, such as the Department of Agriculture's Women, Infants, and Children Supplemental Food Program. In this chapter we are concentrating on the need for additional prenatal care to reduce mental retardation by reducing prematurity and low birth weight.

HEW officials and other authorities have reported that, although there are undoubtedly other factors, insufficient prenatal care can contribute to low weight or premature births. It is generally accepted that increased prenatal care will decrease prematurity and hence mental retardation.

Data compiled by the National Center for Health Statistics for 42 States and the District of Columbia for 1973 showed that 21.1 percent of the babies born to women who received no prenatal care weighed 2,500 grams or less. 1/ The rate of low weight live births for all women was 7.5 percent. These statistics also showed that the rate was 12.5 percent for blacks; 16.5 percent for women under 15 years of age; and 10.1 percent for women 15 to 19 years of age.

The President's Panel on Mental Retardation in its 1962 report stated that (1) very small premature babies are more likely to be mentally retarded (they used a figure of 26.3 percent for those under 1,500 grams compared to 1.6 percent for full term) and (2) there is a greater rate of prematurity among mothers having little or no prenatal care. The Panel also stated that

> "Prevalence of mental retardation tends to be heavily associated with lack of prenatal care, prematurity, and high infant death rates. Women who do not have prenatal care are approximately three times as likely to give birth to premature babies as are women who

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1/ About 5-1/2 pounds

receive adequate prenatal care, and very small premature babies are about 10 times more likely to be mentally retarded than are children of normal births."

In a special report to a subcommittee of the House Appropriations Committee as part of its fiscal year 1975 budget justification, HEW reported that "Researchers have found low birth weight to be a very important factor in stillbirths, in neurological abnormalities, and slow intellectual development."

In fiscal year 1974, 778 children were diagnosed as retarded by mental retardation clinics because of prematurity. This represented 5.9 percent of 13,173 new cases diagnosed as retarded by the clinics that year.

HOW EXTENSIVE IS THE PROBLEM?

National Center for Health Statistics data obtained from 42 States and the District of Columbia showed that, in 1973, about 202,000 of the 2.7 million live births weighed 2,500 grams or less. In the States we visited, low birth weight is a significant problem. In California, about 19,200 babies born in 1973 weighed 2,500 grams or less; in Georgia about 8,300 babies born in 1974 weighed 2,500 grams or less; and in Missouri about 5,200 babies born in 1974 weighed 2,500 grams or less.

Many women do not receive sufficient prenatal care

Authorities recommend that women visit a physician during the first trimester of pregnancy and regularly thereafter. National and State statistics indicate that many women are giving birth to babies without having received sufficient prenatal care. According to the National Center for Health Statistics, about 37,600 women who gave birth in 1973 received no prenatal care and another 60,700 did not get prenatal care until their eighth or ninth month of pregnancy. Of those who received no prenatal care, 21.1 percent gave birth to low birth weight babies.

In California, about 3,800 women who gave birth in 1973 were reported to have received no prenatal care and another 13,500 got prenatal care only in the last 3 months of their pregnancy. These women represented 5.8 percent of the total births that year. Similarly, in Missouri, about 4,500 of the 70,300 women giving birth in 1974 were reported to have

received no prenatal care. In Georgia, 12,400, or 12 percent, of all births were to women who received no prenatal care.

FEDERAL AND STATE PRENATAL CARE PROGRAMS

The maternal and child health program under title V of the Social Security Act is the major Federal resource for providing basic preventive maternal and child health services, including prenatal care, to persons in economically depressed areas. Beginning in fiscal year 1975, each State was required to have a program of projects providing services to mothers and children, including maternity and infant care. Prenatal care is one of the services provided under maternity and infant care projects.

In Missouri, the State maternal and child health services program included:

--Three maternity clinics providing services to Jackson County and the cities of Joplin and Springfield.

--Two maternity and infant care projects providing prenatal care in the city of St. Louis and in St. Louis County. The St. Louis city health department project provides services to approximately 1,200 maternity patients and 2,200 infants annually. The project operated by the St. Louis County health department serves approximately 400 maternity patients annually. The county project discontinued services for infants in 1973 because of limited funds.

--85 health units providing maternal nursing services along with other health services.

--15 full- or part-time public health nurses providing maternal health services.

--Local public health nurses providing expectant parent classes in about 20 counties.

--Prenatal letters providing health information to clients enrolled by physicians, community clinics, or public health facilities.

In 1975 the Missouri legislature established a Bureau of Mental Retardation Prevention, directed by a committee of medical specialists and hospital administrators to provide

services to high-risk women and high-risk infants. Initial funding for the Bureau was limited. However, State officials believed this program will have a significant impact when it is fully operational.

California's department of health supports a network of maternal and child health clinics using a combination of State and Federal funds. The county health departments have administrative responsibility for these clinics. In addition, the State department of health funds, through contracts,

--prenatal and child health services to high-risk populations,

--maternal and child health services to the rural poor and farmworkers, and

--public information and education on maternal and child health.

There were also three federally funded maternity and infant care projects in the State.

Georgia had two federally funded maternity and infant care projects. One was operated by Grady Memorial Hospital in Atlanta; the other by the health department in Richmond County. Together they served 16 of the State's 159 counties. Georgia was also funding its own program of care for medically indigent high-risk pregnant women and infants not eligible for Medicaid.

EXTENT OF UNMET NEED FOR PRENATAL CARE HAS NOT BEEN DETERMINED

The guidelines for maternal and child health services programs of projects published by HEW in September 1976 recognize that many women in low-income families receive little or no prenatal care. The guidelines provide that a State plan for maternal and child health services should indicate the overall nature and extent of the need for such services throughout the State. In selecting areas to be served by maternity and infant care projects, the guidelines state the following factors should be considered: vital statistics, social and economic indexes, and demographic data. An essential element is the number of women reportedly receiving inadequate or no prenatal care. In the States we reviewed, this need has not been adequately analyzed.

In Missouri no studies had been made to identify the extent of unmet need for prenatal care or the areas of greatest need. There was no information on where pregnant women in need of care were located in the State nor on the extent of prenatal care services.

Birth certificates in Missouri showed the trimester of pregnancy during which the mother began receiving prenatal care and the number of prenatal visits. However, the only summary of the data was the maternal and child health services report, which showed for 1974, 4,049 births involving "inadequate prenatal care."

State officials were not sure what "inadequate prenatal care" actually represented. We were referred to an ex-employee of the State department of health who prepared the report. He told us he had used World Health Organization criteria in part in summarizing information from the birth certificates into the category "inadequate prenatal care," but he commented that criteria used were not adequate and that the report was incomplete. At the time of our review, the Missouri Bureau of Mental Retardation Prevention was developing a program to identify and serve women who were at high risk of having a premature or mentally retarded baby.

In California, statistics were available showing, by county and by health district, the incidence of prematurity and low birth weight, the number of women not receiving prenatal care, and, for those women who received prenatal care, the trimester of pregnancy during which care was begun. In addition, at the county level, statistics were available by health district showing average family income, size of family, ethnic composition, age distribution, live birth rates, infant fetal and neonatal death rates, number of women receiving prenatal care, and marital status of pregnant women served. The information, when properly evaluated, may indicate the overall nature, extent, and areas of need for maternity services. However, State officials were unclear as to how this data is used in planning for prenatal care services or evaluating the need for expanded services and were not aware of any recent studies of the unmet need. We noted that some of the data we were provided was 3 to 4 years old and were told that more recent data had not been compiled.

The Director of the California Bureau of Maternal and Child Health indicated that the Bureau does not have the capability or resources to identify the population presently served or those needing services and not receiving them.

Similarly, an official at one maternity and infant care project in California said its heavy patient load has prevented implementation of an active outreach or casefinding program.

The State of Georgia was developing a health care tracking system for prenatal care services. At the time of our review, statistics from birth certificates, death certificates, and certificates of abortion were being computerized and could be summarized by county, health district, and individual hospital. The first printout showing the number of women in Georgia who received no prenatal care was prepared in October 1975 using 1974 data.

The State was also developing a new information collection system whereby health districts and counties will furnish monthly performance reports to the Health Services Research and Statistics Branch which will compare accomplishments to needs for various health programs, including prenatal care. The branch chief told us that Georgia will be able to use the data to establish priorities for allocating prenatal funds. However, we were told that the system will not be in full operation for about 2 years and that the State had not yet determined how it will establish priorities or allocate funds once the system is operational.

PROGRAMS HAVE NOT BEEN EVALUATED AS TO THEIR IMPACT ON PREVENTING MENTAL RETARDATION

Headquarters and regional officials of HEW's Bureau of Community Health Services told us that they had not evaluated the effect of maternity and infant care projects on preventing mental retardation. According to the mental retardation specialist in the Bureau's Office of Special Concerns it is difficult to document the extent of prevention of mental retardation because it would take several years of followup to prove and maternal and child health projects do not have the resources to perform such followup.

HEW regional officials responsible for monitoring maternal and child health programs told us that their evaluation of the impact of programs in the States we reviewed had been minimal. For example, a region 7 official told us that no evaluations had been made of the impact of programs in Missouri. HEW's review of the State plan was primarily geared toward determining if it complied with Federal regulations. A region 9 official told us that due to shortages of staff, monitoring of California's programs had been limited to sending questionnaires to the

administering agencies; the responses had not been evaluated. Region 4 officials told us that the last plan Georgia submitted to the region was in 1972. They said that checklist evaluations had been made subsequently, but they could not locate the certifications.

Similarly, the States we visited had not assessed the impact of prenatal care programs on preventing mental retardation. For example, officials of the Bureau of Maternal and Child Health in California told us that no studies had been made of the impact of their programs on mental retardation. One official said that a major problem in evaluating the impact of these programs has been poor recordkeeping by individual projects, especially the maternity and infant care projects. Another State health official said the shortage of funds was responsible for limited program monitoring and evaluation. He also pointed to a need for more controlled longitudinal studies to better identify the exact link between good prenatal care and prevention of mental retardation before the impact of prenatal care programs can be effectively determined.

CONCLUSIONS

Inadequate prenatal care has been linked to premature and low weight births which are in turn linked to mental retardation. National and State statistics indicate that many women still receive insufficient prenatal care, even though Federal and State programs have been established to reach persons in economically depressed areas who might not otherwise receive such services. The extent of need for additional services is unknown because neither HEW nor the States have adequately analyzed (1) the extent of the current needs for prenatal care, (2) the areas of greatest needs, or (3) the effect of existing programs.

RECOMMENDATION

To be able to establish priorities for allocating prenatal care funds most effectively and to the areas of greatest need, we recommend that the Secretary of HEW direct the Bureau of Community Health Services to evaluate the State procedures used to determine needs for prenatal care services and insure that State plans outline a clear strategy of how to reach the population in greatest need.

AGENCY COMMENTS

HEW concurred in our recommendation and pointed out that based on a State-by-State assessment of high infant mortality and morbidity distribution, the Bureau of Community Health Services has initiated State-wide Improved Pregnancy Outcome projects in nine States. An additional nine States are expected to be added in fiscal year 1977. HEW advised us that the Health Services Administration was aware that in many States the unmet need for prenatal care has not been sufficiently analyzed and that this was an element of its Child Health Strategy for fiscal years 1978-82.

CHAPTER 5

IDENTIFYING PERSONS IN NEED OF GENETIC TESTING AND COUNSELING

Chromosome abnormalities are estimated to account for about 16 percent of the clinically caused cases of mental retardation. A 1974 study reported that over 10 percent of the residents of public residential facilities for the mentally retarded reporting such information were diagnosed as having a chromosome abnormality. Down's syndrome (mongolism), one of the most common of such abnormalities, appears in about 1 in 650-1,000 births and, at one time, accounted for 15 to 20 percent of the institutionalized mentally retarded.

Since treatment of chromosome abnormalities is limited, the main role of medical genetics is prevention through genetic counseling and testing. Persons with chromosome defects, or at high risk of having children with defects, can be identified and counseled. Additionally, chromosome abnormalities can be diagnosed in an unborn child, thus allowing the parents to make an informed decision about continuing the pregnancy.

However, it appears that only a small portion of those who could benefit from genetic services receive them. Neither HEW nor the States we reviewed have made efforts to assure that persons needing the service or at risk are screened or served. In addition, the geneticists we interviewed generally believed that only a small percentage of those who obtain services are from lower socioeconomic groups.

Federally funded family planning programs, and possibly other Federal programs, might be a good means of providing the needed outreach and identification and for serving lower income families. However, the family planning programs in the States we reviewed generally did not attempt to identify families in need of genetic services. The federally funded maternity and infant care projects we visited were referring high-risk clients for genetic services.

Most geneticists we interviewed believed that if family planning programs were to identify and refer clients in need of genetic counseling and testing, existing clinics and laboratories could meet the demand. However, PCMR and Bureau of Community Health Services officials advised us that, for the laboratories to meet the demand, additional capacity, primarily

equipment, would be needed. CDC officials were of the opinion that the laboratories would be overwhelmed. The extent to which existing clinics and laboratories could meet the demand would depend on the number of clients referred and the geographic area.

CHROMOSOME ABNORMALITIES ARE DETECTABLE

Some chromosome abnormalities are passed on from either one or both parents to the child. A chromosome disorder may also appear in a child because of a genetic accident or damage caused by drugs or radiation even though the parents are genetically normal. In both instances, prevention consists primarily of attempting to forestall the birth of affected infants, but the form of prevention varies. Inherited disorders can be prevented by identifying carriers of traits and informing them on the odds of having an affected child. Disorders that occur by genetic accident or damage must necessarily be diagnosed after conception.

A recently developed procedure has made it possible to make a firm determination about certain defects well before birth. The procedure, called amniocentesis, entails withdrawing a small amount of the amniotic fluid which surrounds the fetus in the uterus. The fluid, containing fetal cells which can be cultured and evaluated, provides information on the chromosomal make up of the unborn child. If a defect should be identified and the physician knows about it early in pregnancy the doctor is in a better position to minimize damage through prompt action at or soon after birth. The impact can be minimized by overcoming the physical problems (cleft palate, congenital heart defects, etc.). In addition, certain programs can reportedly minimize the retardation in Down's syndrome children through intensive infant stimulation and early intervention, using methods similar to those discussed on page 82. Parents, too, can make an informed judgment about continuing the pregnancy.

The procedure is useful not only for detecting disorders that arise by reproductive accident, but is also a valuable tool for family planning where one or, rarely, both parents carry a genetic disorder. Because of the availability of amniocentesis, such parents can be less apprehensive when trying to have a baby. One geneticist told us that his referrals are primarily from abortion clinics. His clients are women who have previously borne children with genetic disorders and now, again pregnant, are seeking an abortion rather than

risk having another defective child. In the vast majority of cases where amniocentesis is performed, the infant turns out to be normal. Thus, many children have been saved that may otherwise have been aborted.

In October 1975, the National Institutes of Health reported on a national study which compared 1,040 women who chose to undergo amniocentesis with a matched control group of 992 who didn't. The study showed that the diagnostic procedure itself poses no additional risks to pregnancy and that the procedure was more than 99 percent accurate. The project director recommended the procedure for women over 35 and for those with a family history of genetic disorders.

As discussed on page 32, the recently enacted National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act could have an impact on providing genetic counseling and testing services. However, the program has not yet been implemented.

SOME HIGH-RISK INDIVIDUALS ARE IDENTIFIABLE

Essential information needed for adequate genetic counseling includes a detailed family history, a specific diagnosis, and knowledge of the inheritance patterns of the disorder. Diagnosis of the specific disorder requires chromosome analysis using one or more of the available techniques of chromosome study. A complete chromosomal analysis, not including amniocentesis, costs up to $300; amniocentesis can cost as much as $300 more. Due to this high cost, it is not practical to screen the population at large. However, certain "high-risk" individuals can be identified through less sophisticated, inexpensive techniques such as interview or visual observation.

For example, families with a previous child having a chromosome abnormality are likely candidates for genetic studies and counseling. Other indications of high risk for a chromosome defect include

--mother over age 35,

--two or more congenital malformations,

--mental retardation,

--failure to develop secondary sexual characteristics, or

--multiple miscarriages.

If an individual is identified as having one or more of these factors, he or she can be referred to an appropriate facility for more in-depth study and counseling.

There are also indications of high risk for the types of chromosomal abnormality that arise as a genetic accident in a particular conception; for example, maternal age is a high risk factor for Down's syndrome. As a woman's age increases, so does the chance that she will bear a Down's syndrome child as a result of reproductive accident. The chance of a 20-year-old woman having a Down's syndrome baby is only about 1 in 2,000, but by 35 the frequency is about 8 times greater. 1/ Although only 7 percent of all live births in the United States are to mothers 35 or older, they contribute one-third of the estimated 7,000 Down's syndrome babies born each year.

CURRENT PREVENTION EFFORTS ARE LIMITED

In the States we visited, identification and counseling of high-risk families appeared to be limited. In California, for example, the exact extent of genetic testing being done was not known, but geneticists at major medical centers estimated that only about 5,000 to 6,000 chromosome analyses are being done statewide each year.

In Missouri, we could not determine how many people were receiving or in need of genetic services, but we found that most technical genetic services were primarily limited to seven genetic service providers in the State. Only one laboratory in the State was analyzing amniotic fluid to detect chromosome defects. The State has 11 regional centers for the developmentally disabled where diagnosis, counseling, and referral services are provided. However, these services are directed primarily to reducing the impact of mental retardation, rather than prevention.

In Georgia, the Director of the State's maternal health program told us that only three facilities were providing genetic screening and counseling.

In all three States we were told that that the testing that is being performed is generally limited to families where

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1/ We were advised by a genetic expert in November 1976 that recent statistics indicate that the frequency of occurrence in women over 35 may be greater than previously estimated.

there is already a retarded child or suspicion of a genetic defect. For example, all but 20 of 1,060 chromosome studies done at the Georgia Retardation Center during the 4 years ending October 30, 1975, were for mentally retarded patients and their families. Even so, it has been estimated that less than 5 percent of the families of the retarded receive genetic counseling.

The genetic service providers we contacted generally performed testing and/or counseling for clients referred to them by other sources, usually private physicians, hospitals, or mental retardation clinics; they did not attempt to identify high-risk individuals. They said they did not have the resources or the time to go out looking for business. They usually got all they could handle through referrals.

We questioned geneticists in the States we visited about the socioeconomic status of most families obtaining genetic services. None of these geneticists had any comprehensive data, but they agreed that, in general, most persons presently receiving genetic services are from upper socioeconomic groups. They agreed there is a need to make genetic services more readily available to the lower socioeconomic groups.

FAMILY PLANNING PROGRAMS COULD IDENTIFY HIGH-RISK CLIENTS BUT GENERALLY DO NOT

Officials in Missouri, Georgia, and California stated that, if mandated and funded, family planning clinics would be a good vehicle for providing referrals for genetic services. Family planning programs serve many women for whom genetic information would be useful. Also, many women served are high risk for genetic disorders (an estimated 7.5 percent are 35 years of age or older) and most are from low-income families.

In fiscal year 1974, 3.4 million women were served in organized family planning programs in the United States. One family planning official in Los Angeles said that more women come in contact with family planning programs than any other health service. A substantial proportion of the women seeking family planning services are interested in obtaining information on optimal child rearing and child spacing. For example, about 44 percent of the women seen by family planning clinics in Los Angeles County who responded to the question, indicated that they planned to have children. Genetic counseling could provide information relevant to such plans for women identified as being possible carriers of chromosomal abnormalities.

In addition, a Los Angeles family planning official said many women come to family planning clinics seeking information on abortion. This official was convinced that many women are seeking abortions because they have had a previous child with a genetic problem. If these women were specifically identified and provided initial genetic information before being referred to an abortion clinic, the abortion might be avoided if the fetus was found to be normal.

Many women served by family planning clinics risk having children with Down's syndrome because of the women's age. Nationally, about 7.5 percent of the women served by organized family planning programs in 1974 were 35 years of age or older. These women could be advised of the risks and told of the available tests in the event they decide to have children.

Finally, family planning programs would be a good vehicle for reaching lower socioeconomic families with genetic screening services because most women served in family planning programs are from low-income families. HEW estimated that in fiscal year 1974, 54 percent of the women served by organized family planning programs were members of families with income at or below the national poverty level; an estimated 73 percent had annual incomes at or below $7,557--150 percent of poverty level for a family of four.

Federally supported family planning programs were operating in each State we reviewed. However, the programs generally did not consider it part of their mandate to identify families needing genetic services. State family planning officials in Georgia and Missouri stated that although identifying persons at high risk for genetic disorders is not currently one of their mandates, the family planning clinics would be an ideal vehicle to provide this service because of their contact with high-risk people.

California standards for family planning services provide, in part, that the medical services that must be provided to each patient include (1) obtaining a complete obstetrical history, including complications of any pregnancy, and (2) a relevant family health history, including any genetic problems. However, the head of the State family planning programs told us that the standards are only advisory, not mandatory, and the actual services rendered are totally within the treating physician's discretion.

Some family planning services in California were affiliated with medical centers as part of a system of integrated comprehensive health care. Officials at some of these programs indicated that their clients received genetic services as part of that care. However, we noted that the medical forms used by the family planning services did not provide for collecting information which would indicate a high risk for a genetic problem other than the patient's age. Also the clinic had no procedures to identify genetic problems, and no records were available on patients referred for genetic studies. One clinic did require that all women over 35 be under the care of a physician.

Eight out of nine geneticists we interviewed told us that they believed existing genetic clinics and laboratories if properly funded had adequate capacity to absorb additional demand for services that might be created if family planning programs performed initial genetic screening and referred clients for services. The National Academy of Sciences has reported that a shortage of genetic counselors is also a hurdle to expanded screening, but some efforts are underway to alleviate this shortage. According to the Academy, the role of the primary physician makes him the ideal counselor. The Medical Director of the California Department of Health Developmental Services Program, Treatment Services Division, told us that about three-fourths of all counseling required could be done by pediatricians and obstetricians once they are provided the laboratory results and interpretative information. In addition, some schools have begun to train nonphysician college graduates to be genetic counselors.

HEW regulations do not specify whether genetic counseling should or could be included in title V family planning projects. Title X guidelines include genetic counseling as an optional service.

CONCLUSIONS

Mental retardation can be reduced through genetic screening and counseling, but only a small proportion of those who could benefit from such services appear to be receiving them. Providers of genetic services generally perform little outreach and serve primarily higher income groups.

Since federally supported family planning programs provide services to a large number of women from lower socioeconomic families, they seem to be a good vehicle for identifying high-risk families and individuals in the lower

socioeconomic groups. Other Federal programs, such as community health centers, might also be able to provide similar services.

RECOMMENDATIONS

We recommend that the Secretary of HEW:

--Direct federally supported family planning programs to routinely include screening for individuals who are "high risk" for genetic disorders and refer such individuals to diagnostic and counseling services.

--Monitor the demand on existing genetic resources created by outreach and develop strategies for increasing resources as needed.

--Explore how other Federal programs could better be used to provide genetic screening and services.

AGENCY COMMENTS AND OUR EVALUATION

HEW agreed generally with our recommendations but stated that it could not mandate universal screening until more capacity for effective screening and counseling is available. The Department stated that the demand on existing genetic resources at present exceeds their capacity.

With respect to monitoring the demand on existing genetic resources, HEW stated that the continued monitoring of the demand is most important in implementing our recommendations to assure that the demands generated by any outreach and additional screening can be dealt with by the centers. Both the child health strategy and the genetic diseases implementation plan stress statewide networks with the State health department playing the key role in establishing linkages between screening and provider programs. HEW advised us that with the establishment of a focal point in HEW for the mental retardation prevention effort, it will be possible to work out a mechanism to include these activities in other Federal programs.

We agree with HEW that it cannot mandate screening and referral of high-risk persons for genetic counseling and testing if the necessary diagnostic and counseling services are not available. However, it should mandate screening and referral where the services are available.

CHAPTER 6

IMPROVING IMMUNIZATION LEVELS FOR RUBELLA AND MEASLES

Federal programs can improve national surveillance data and help prevent mental retardation by helping to raise immunity levels for rubella and measles. The Medicaid Early and Periodic Screening, Diagnosis, and Treatment program could collect and provide immunization surveillance data to the Center for Disease Control and increase immunization levels among the children served; Head Start programs could collect and provide CDC with immunity level data on the children they serve; and federally funded family planning programs could screen its women clients and provide immunizations to those in need.

As indicated on page 4, rubella and measles can cause mental retardation. CDC estimates that about 1 of every 1,000 reported cases of measles results in brain inflammation and that about 25 to 35 percent of those cases result in mental retardation. CDC has also estimated that the 1964-65 rubella epidemic caused about 1,800 cases of mental retardation, about 2,200 deaths, about 6,300 miscarriages, left about 12,000 children deaf or deaf-blind, and caused 5,000 women to seek therapeutic abortions.

In the 1960s vaccines against both these diseases became available and since then the incidence of each disease has dropped dramatically. However, CDC reports that cases are still occurring and that immunity levels are unnecessarily low, particularly among preschool children, giving rise to the possibility of a major epidemic.

From a national perspective, two elements are necessary to effectively combat these diseases: comprehensive data on immunity levels to pinpoint problem areas and aggressive immunization programs targeted at areas with low immunity levels. However, in the past, immunity level data has not been adequate to pinpoint problem areas, nor have vaccination programs raised immunity to acceptable levels.

Federal funding for immunization projects has been substantially reduced since 1970 on the premise that Federal programs, such as EPSDT, and the States themselves would be assuming increasing responsibilities for immunizing children. However, CDC is concerned that as Federal funds continue to be reduced, immunization efforts will falter because EPSDT and States are not effectively taking up the slack.

MENTAL RETARDATION CAUSED BY MEASLES AND RUBELLA CAN BE PREVENTED

In 1963 a measles vaccine became available for general use in the United States. In 1969 a similar vaccine for rubella became available. Since then, the primary prevention approach has been to try to immunize all children. According to the Deputy Director of CDC's Immunization Division, at least 95 percent of all children should be immunized before they enter school.

As of September 1975, 45 States, including the 3 we visited, had laws or regulations requiring measles immunization before school entry; 38, including Georgia and Missouri, required rubella immunization before school entry.

In addition to vaccinating school-age children, mental retardation caused by congenital 1/ rubella can be prevented by identifying women of child-bearing age who are not immune to rubella and vaccinating them before they become pregnant. It is estimated that 10 percent of all pregnant women are at risk of contracting rubella. A blood sample can be analyzed to determine whether an individual has developed an immunity to rubella.

California has adopted this approach. Although vaccination of preschool and school-age children for rubella is strongly encouraged by State health officials, it is not required. The State law does require, though, that every woman applying for a marriage license have a blood test to determine if she is immune to rubella. If she is susceptible, the doctor performing the test counsels her on the risks of getting rubella during pregnancy and suggests that she be vaccinated. According to CDC, two other States have mandatory rubella screening programs.

CDC officials stated that premarital rubella testing programs have not been highly successful because the women tested either did not receive the test results or did not take action on them. Normally, the laboratory sends the test results to the doctor who took the blood sample. In many instances, a woman who went to a doctor solely for a premarital blood test would not see him again and would not receive the results of the test or counseling on immunization. Another problem with premarital testing and vaccination is

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1/Damage to the unborn child caused by the mother contracting rubella during the first trimester of pregnancy.

is the danger that the vaccine might cause damage if given to a pregnant woman or if a woman becomes pregnant shortly after immunization.

Vaccination programs have been instrumental in preventing rubella and measles. The incidence of rubella has dropped from over 57,000 reported cases in 1969 to about 12,000 in 1976. Measles incidence has dropped from about 385,000 reported cases in 1963 to about 40,000 in 1976. CDC estimated that for 1963-72, vaccination programs prevented almost 24 million cases of measles, saved 2,400 lives, and prevented 7,900 cases of mental retardation, resulting in savings of about $1.3 billion. Despite these advances, CDC still considers immunity levels to be too low; disease and unnecessary deaths still occur.

BETTER DATA IS NEEDED ON IMMUNITY LEVELS

A major hindrance to improving immunity levels appears to be the absence of good surveillance data. Without reliable data, health officials can identify neither the areas in greatest need nor the States with the most successful programs, which could make their methods available to other States.

Before 1968, CDC required quarterly progress reports in conjunction with grants-in-aid to the States to support vaccination programs. However, under HEW's regionalization approach, the authority for making the grants was shifted to HEW regional offices; CDC continued to maintain surveillance data, but reporting by States became voluntary.

CDC presently uses two principal sources of immunity level data: The United States Immunization Survey and immunization project status reports. However, the data collected is considered usable only for analyzing national disease patterns and trends and not for identifying States or areas within States where immunity levels are low.

U.S. Immunization Survey

The Bureau of the Census in cooperation with CDC conducts the U.S. Immunization Survey every September. Census collects immunization data through a supplemental questionnaire attached to the monthly Current Population Survey. In September 1975, the sample consisted of 35,000 housing units distributed throughout the United States.

Although CDC feels this survey provides the most accurate data available on immunity levels, it is not extensive enough to enable CDC to pinpoint specific States, or areas

within States, with low immunity levels which should be given special attention. One CDC official stated that the cost of expanding the survey so that it could provide enough detailed information to pinpoint specific problem areas would be prohibitive. Hence, alternative approaches are required.

We were informed by HEW that subsequent to the completion of our fieldwork, CDC had completed an evaluation of the survey. Recommended changes in the survey have been approved and the Bureau of the Census has implemented the changes.

Project status reports

CDC grants support vaccination programs in each State. CDC receives periodic reports on the status of these programs; the number of doses of vaccine administered are reported monthly and immunity levels are reported annually. However, CDC believes this data does not provide an accurate indication of immunity status in a given State because (1) the reported number of doses of vaccine administered are only those given through public programs and not by private physicians and (2) the reports reflect only the vaccinations given at school entry and do not reflect children subsequently immunized.

CDC efforts to improve data

To improve immunity level data, CDC issued guidelines to the States in 1973 for assessing immunity levels. The guidelines call for (1) compiling data of immunity levels of each child at school entry and (2) conducting stratified random sample surveys of 2-year-old children. According to CDC, the data reported by the States has improved since the guidelines were issued, especially the school entry data, but information on preschool children is still sparse.

The 1975 U.S. Immunization Survey indicates that immunity levels among preschool children are lower than those of children in the 5 to 9 age group. Nationally, only two-thirds of the children between the ages of 1 and 4 are immune to rubella and measles; in some areas the immunity level is as low as 60 percent for this age group.

In the immunity level assessment guidelines, CDC has pointed out the advantages of surveying 2-year-olds, including:

--Children should have completed their basic series of immunization by this age.

--Immunization levels in 2-year-olds are indicative of levels in both younger and older children.

--A large portion of data can be gathered by mail-out questionnaires.

--Birth certificates, used as a sampling base, are easily accessible and fairly standard from community to community.

However, for 1974 only 35 States had conducted measles and rubella surveys of 2-year-olds and reported the results to CDC. CDC officials stated that under the present Federal grant management system, State reporting is voluntary; thus CDC cannot compel States to conduct surveys or report results.

MORE AGGRESSIVE VACCINATION EFFORTS ARE NEEDED

Even though most States have laws or regulations requiring immunization for measles and rubella before school entry, the U.S. Immunization Survey indicates that not enough children are being vaccinated. CDC has not officially established minimum levels or goals; however, CDC officials said that an 85-percent level would normally be needed to protect localized sections of the population from epidemics. The level depends on disease communicability, population mobility, and population density. One CDC official stated that a 95-percent level would be a reasonable measles immunity goal. The 1975 survey showed that, nationwide, about 74 percent of children between the ages of 5 and 9 had been vaccinated for measles and about 70 percent for rubella; in some regions average vaccination levels for this age group were as low as 72 percent for measles and 61 percent for rubella.

Of even greater concern to CDC is the need to raise immunity levels of preschool children. In a 1974 survey, only 4 States reported that 90 percent or more of its 2-year-olds were immune to measles and none of the 35 reporting States had reached a 90-percent immunity level for rubella. One State reported that only 57 percent of the 2-year-olds surveyed had been immunized against measles, and only 36 percent had been immunized against rubella.

Our 1974 report 1/ described some of the problems in achieving and maintaining acceptable immunization levels:

1/"Review of Selected Communicable Disease Control Efforts," B-164031(2), June 10, 1974.

--Apathy by physicians, public health officials, and the general public toward raising immunization levels.

--Inadequate enforcement of laws requiring immunization, especially for preschool children.

--Insufficient resources to continously operate comprehensive immunization programs.

CDC officials said that the last factor was a major cause.

Federal immunization project grant funds have been reduced from $16 million in fiscal year 1971 to less than $5 million in fiscal year 1976. The reductions have been made primarily on the assumption that the States would support an increased share of the costs. However, increased demand on States funds for other health care needs has precluded this from happening.

CDC officials expressed concern that if present reductions of Federal immunization project grant funds continue, immunity levels will fall because States cannot take up the slack. They cite as an example the experience with measles in the late 1960s. Trend data shows that after grant assistance was initiated in 1966, the number of reported measles cases and deaths from measles dropped dramatically. But when these grants ended in 1968 and 1969, the number of reported cases and deaths more than tripled until the projects were reinitiated in 1971 at which time the incidence and deaths again declined. CDC officials estimate that about $10 to $15 million in Federal grant funds are needed to maintain current immunity levels.

FEDERAL PROGRAMS COULD HELP

Certain Federal programs, in particular EPSDT, Head Start, and family planning programs can improve surveillance data and raise immunity levels.

Early and Periodic Screening, Diagnosis, and Treatment

Since 1972, all States participating in the Medicaid program have been required to provide EPSTD as part of their Medicaid programs. The screening program presents an excellent opportunity to determine a child's immunization status. In fact, screening for immunization status is included among the Medicaid-recommended minimum elements of screening.

However, EPSDT's reporting system does not provide the surveillance data necessary to identify areas needing more aggressive immunization activity. The EPSDT monthly reports submitted to HEW show the total number of individuals screened, but not the number screened for any particular condition; it is not possible to determine how many children have been checked for immunization status or the immunity levels found. A CDC official indicated that reporting under Medicaid programs is based on physician billings for services rather than being set up specifically to collect surveillance data.

The three States we visited had EPSDT programs, but information had not been compiled on immunity levels of children screened, numbers of children screened for immunization status, or the number of individuals immunized under the program.

CDC has proposed two methods by which EPSDT could improve vaccination efforts. Clinics could be directly reimbursed by Medicaid for immunizations given to eligible children. However, CDC would prefer that CDC and the Social and Rehabilitation Service enter into an interagency agreement whereby EPSDT would annually pay for, under CDC's bulk purchase agreement, enough unit doses of vaccine to immunize the children expected to be identified through EPSDT screening in a given State. The vaccine could then be provided to the State for distribution through its public health clinics. The agreement could be adjusted annually based on actual vaccine usage. According to CDC, the proposal has not been accepted within HEW.

The Deputy Director of CDC's Bureau of State Services told us that one reason Federal immunization grant funds were reduced was that EPSDT was expected to take up much of the slack by identifying and immunizing children in need. However, the Social and Rehabilitation Service has a policy of not paying for services with Medicaid funds that could be provided free of charge through public health programs. Thus, the expectation has not been realized.

Head Start

Head Start program guidelines require that each enrollee have a physical examination, including screening for immunization status. Before fiscal year 1976, Head Start projects collected immunization data on polio, diphtheria, whooping cough, tetanus, measles, mumps, and rubella through its Health Program Assessment Report. A CDC official told us that CDC had helped the Office of Child Development develop this surveillance system and, in the past, had received information on immunity levels from Head Start projects.

However, CDC no longer receives the information because in 1975, Head Start stopped using the Health Program Assessment Report and began a grantee self-assessment system. The self-assessment system calls for checking child records for completion of immunizations as part of the assessment process; however, it does not provide data on the number of children immunized. It appears that some immunity level data could be compiled during this assessment and reported to CDC. CDC officials told us that they believe information from EPSDT and Head Start would be especially valuable as an indication of immunity levels among children from lower socioeconomic backgrounds. A Head Start official informed us that Head Start had no system for compiling data on immunization levels but is attempting to develop such data through its management information system.

Family planning

Family planning programs could screen women for rubella susceptibility and recommend vaccination to those not immune. There are four advantages to using family planning programs for such screening. First, organized family planning programs reach a large number of women--about 3 million a year. Second, blood testing is done routinely as part of family planning services; the Director of the Oregon State laboratory said that rubella susceptibility testing could probably be added for about a dollar. Third, the risks of a woman becoming pregnant shortly after immunization are minimized by the fact that in visiting the family planning program, she is probably seeking contraceptive services. Finally, family planning clinics could also reach women who could not be reached by premarital screening programs.

Rubella susceptibility testing was not being done by family planning programs in California and Georgia. In Missouri, we could not determine what was being done statewide but rubella testing was not conducted at the two clinics we visited. HEW regulations do not specify whether rubella susceptibility testing should or could be included in title V family planning projects. Title X guidelines do authorize such testing. We were told that family planning programs in Oregon routinely screen women for rubella immunity, and, the director of the State laboratory thought the program was generally successful.

CONCLUSIONS

Mental retardation caused by rubella and measles can be prevented by aggressive vaccination programs. However, since

rubella and measles immunization levels are less than considered necessary, expanded efforts to immunize children and to test women of child-bearing age for susceptibility to rubella are needed. Better data is needed on immunity levels in local areas. Certain Federal programs, such as EPSDT, Head Start, and family planning could improve surveillance data and raise immunity levels.

RECOMMENDATIONS

We recommend that the Secretary of HEW:

--Examine the alternatives of expanding CDC support of State vaccination programs or making arrangements between CDC and the Medical Services Administration that will enable EPSDT to more effectively support national and State immunization activities.

--Expand EPSDT requirements to specifically require screening for immunization status and reporting of the number screened and immunized.

--Require Head Start projects to develop data on the results of their immunization screening.

--Require federally funded family planning and other appropriate programs to include rubella susceptibility testing and immunizations, where appropriate, among their routine services.

AGENCY COMMENTS

HEW agreed with our recommendations. We were advised that the draft of a proposed revision to the EPSDT penalty regulation will require that the immunization status of each Medicaid recipient be determined at the time the screening test is performed. HEW is revising the EPSDT reporting requirements to include reporting on inadequate immunization status found through screening.

The Department also advised us that it has proposed legislation to convert EPSDT to a Comprehensive Health Assessments and Primary Care for Children Initiative which will address these issues. This has been introduced as H.R. 6706 and S. 1392.

CHAPTER 7

INCREASED SCREENING TO DETECT LEAD POISONING

More widespread screening is needed to determine the extent of the lead poisoning problem. A recent breakthrough in testing techniques has made it possible to inexpensively expand testing. However, except in certain known high-risk areas, lead poisoning is not a recognized problem, and screening is not routine. Even Medicaid's EPSDT program, which strongly encourages lead screening, apparently does not perform such screening on a large scale; reporting requirements are inadequate to determine the extent of screening and the results in locales where screening is going on.

As indicated in chapter 1, lead is a lethal poison that can result in death, mental retardation, and other handicaps. Children between 1 and 6 years of age are its main victims. The impact of lead poisoning as a cause of mental retardation and other handicaps can be reduced by screening children to detect elevated lead levels, treating those identified, and eliminating sources of or exposure to lead.

Lead poisoning has generally been associated with children eating lead-based paint chips. Steps have been undertaken to reduce lead poisoning hazards, including urban renewal and laws restricting lead-based paint. Recent studies show, however, that other sources of lead, such as airborne emissions from automobiles or smelters, may be causing excessive lead absorption in other segments of the population.

RECOGNIZING THE PROBLEM

A major hurdle to preventing and treating lead poisoning is the general lack of awareness of the conditions and the difficulty of recognizing it in children. It is impossible to identify which children have absorbed undue amounts of lead except through specific testing. First, levels of the lead which are not sufficient to produce any overt symptoms of poisoning can nevertheless impair health and behavior. Second, even where symptoms are present, they are nonspecific for lead poisoning (constipation, loss of appetite, vomiting, irritability, listlessness, and cramps) and will often be misdiagnosed unless the physician strongly suspects lead poisoning. The symptoms are often attributed to other childhood illnesses.

Experts do not agree on the level of lead in the blood which can be considered "normal" or "safe." CDC has defined lead poisoning as (1) a confirmed (two successive determinations)

blood lead equal to or greater than 80 micrograms of lead per 100 milliliters of blood with or without symptoms, (2) erythrocyte protoporphyrin level equal to or greater than 190 micrograms of lead per 100 milliliters of blood with or without symptoms, (3) 50 to 79 micrograms of lead per 100 milliliters of blood with compatible symptoms which cannot be explained otherwise, or (4) erythrocyte protoporphyrin level of 110 to 189 micrograms of lead per 100 milliliters of blood with compatible symptoms which cannot be explained otherwise. All are considered to require immediate treatment. The effects of lesser amounts of lead are not clearly known, but studies have shown that mental impairment can occur at levels down to 40 micrograms of lead per 100 milliliters of blood. 1/ As a result, anything over this level is generally considered "elevated" and warrants intervention even without symptoms of lead poisoning.

Without specific screening for lead poisoning, the extent of the problem cannot be fully identified. It is also difficult to determine the incidence of retardation caused by lead poisoning, but according to HEW, it is probably not infrequent. In one study of 425 children with lead poisoning, mental retardation was the most frequent consequence, occurring in 22 percent of the cases. The American Academy of Pediatrics has reported that at least 25 percent of children with lead poisoning are left with permanent central nervous system damage; even higher incidence has been reported by other investigators.

In 1972 HEW estimated that at any given time about 600,000 children have elevated blood lead levels. This includes about 6,000 children with neurological handicaps, including mental retardation; about 200 children that die annually; and about 150 children requiring lifetime institutional care as a result of lead poisoning. It was estimated that lead poisoning costs about $195 million a year, including hospitalization costs, loss of earnings, added educational expenses, and the costs of lifetime care. In commenting on a draft of this report, HEW advised us that this estimate is now probably very low. HEW added that there is compelling data that low level chronic toxicity impairs neurological development in the very young and results in significant educational underachievement and hyperactivity. In the first 9 months of fiscal year 1975, HEW-funded screening programs

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1/In 1975 CDC defined "undue lead absorption" as 30 to 79 micrograms of lead per 100 milliliters of blood. In this report we have used "elevated" to mean 40 micrograms or greater.

identified about 4,600 children with elevated lead levels, or about 14 percent of the children screened.

SOURCES OF LEAD

Before 1955, lead-based paints were used extensively for interior painting. Most cases of lead poisoning have been found in children living in poorly maintained older homes and apartments, and most efforts to combat lead poisoning have concentrated on eliminating lead-based paint from houses and apartments. Lead poisoning continues to be viewed by many as restricted to slums and poverty conditions.

However, lead poisoning is not confined to the inner city or restricted to the poor. For example, in areas with newer housing some exterior paints still contain lead.

Airborne lead has become a subject of great interest since 1972. Studies of children living near lead smelters have shown that breathing particles in the air and ingesting the dust appears to cause elevated lead levels. Studies by the Environmental Protection Agency indicated that breathing automobile exhaust laden air dramatically increases the levels of lead in the blood and that samples of street dirt and house dust in urban areas have revealed concentrations of lead greater than those considered safe in paint. Other studies have shown that soil and vegetation alongside roads contain high amounts of lead resulting from automobile exhaust. Other potential sources of lead poisoning include certain canned foods, ink used in childrens' books and magazines, evaporated milk, baby food, silver-plated baby cups, and water supplies.

INEXPENSIVE SCREENING TECHNIQUES ARE AVAILABLE

One limitation to widespread screening has been the cost. For example, about 444,000 high-risk children were screened in federally funded projects in fiscal year 1975 at a cost of about $20 a child. However, a recent breakthrough in screening techniques makes it possible to expand screening to relatively low-risk areas, such as suburbs and rural areas.

One test, called the FEP test (free erythrocyte protoporphyrin), uses a dried blood sample collected on filter paper exactly as it is used for PKU. (See p. 24.) In some instances, it can detect a case of lead absorption when lead concentration itself is too low to be considered positive and would be missed by the standard technique. The test

will also identify cases of iron deficiency 1/ anemia because anemic children also have elevated FEP levels.

Almost anyone can be quickly taught to collect the dry blood specimen, so trained volunteers can be used. In addition, the blood specimens can be collected in one place and mailed to a center where large volumes of the test can be carried out inexpensively with less possibility of contamination. The original developer of the test and a State laboratory official who refined it said the test can be performed for about $2. CDC recommends that the FEP test be used for screening, followed by a blood lead level test for all children found to have elevated FEP levels.

Another method of screening is also available which tests for lead poisoning and anemia by measuring zinc protoporphyrin in a small blood sample. CDC estimates that the total cost of laboratory equipment and personnel is about 10 cents per child in high-volume areas, although they pointed out that laboratory costs are only a small portion of the total cost of screening. A small portable machine for this test has been constructed and at the time of our field work was being field tested. We were subsequently advised that the field tests have been completed and the instruments are coming into wide use.

Although the amount of screening needed for States to identify the extent of the problem by area varies, it probably would not involve screening every child. We estimated, though, that even if all children under 5 years of age were screened and those needing treatment were treated, the total cost would probably be about $70.5 million as shown on the following page.

1/It will also detect iron deficiency even before anemia ensues.

Estimated cost of initial screening: (20 million @ $2)	$40,000,000
Estimated cost of confirmation testing: (600,000 @ $5)	3,000,000
Estimated cost of chelation treatment: (note a) (110,000 @ $250)	27,500,000
Total	b/ $70,500,000

a/Reducing the blood lead level by injecting the patient with a chemical which combines with lead and draws it out of the circulatory system so it can be excreted from the body.

b/Due to absence of exact data on the incidence of lead poisoning, these computations were based on gross HEW estimates. This analysis is presented solely as a general indication of the advantages of prevention.

Although the costs of screening and treatment appear to be high, they are much lower than the $195 million HEW has estimated lead poisoning costs the country annually in hospitalization, lost earnings, added special education, and lifetime care. Also, it should be noted that in the years following the initial testing, the costs of screening could probably be reduced because areas shown to have a low yield of lead poisoning can be eliminated from screening and resources could be focused on problem areas. Also, the cost of chelation therapy would drop as more children are identified before their lead levels become so high as to require chelation.

As discussed on page 62, HEW believes its $195 million estimate of the cost of lead poisoning may now be very low. In addition, HEW believes the $250 cost for chelation treatment may also now be very low because most practitioners now prefer affected children be hospitalized for the treatment which lasts 5 days. They added that hospitalization of 14 to 21 days is not unusual for symptomatic cases, followed by 1 to 6 months of outpatient therapy.

FEDERAL AND STATE EFFORTS HAVE BEEN MINIMAL

Since fiscal year 1972 CDC has awarded project grants to selected communities to screen children for elevated levels of lead in the blood. In addition, grants are used to help develop State laboratory capabilities in lead

analysis, setting and enforcing standards, and monitoring performance of local laboratories. CDC also cooperates with other Federal agencies who have responsibilities in areas related to childhood lead poisoning, such as the Department of Housing and Urban Development, Maternal and Child Health programs, and the EPSDT program.

Other Federal efforts to prevent lead poisoning include public education activities by HEW's Bureau of Community Health Services, lead screening by some children and youth projects, special screening projects financed through maternal and child health programs, and research grants to study effects of lead exposure. However, if the problem is to be eliminated, expanded screening is needed as a first step to identify its full extent and increase public awareness of lead poisoning and support for its elimination.

The Director of CDC, in a June 1975 statement before the Senate Subcommittee on Health of the Committee on Labor and Public Welfare (now Committee on Human Resources), reiterated the importance of expanded screening. Objecting to legislation which would prevent child screening grants from being awarded to a community unless assurances were present that a lead-based paint program would be carried out, the Director said that elimination of lead-based paint hazards in the homes of children who have elevated blood lead levels would be costly and would reduce the amount of funds available for screening and pediatric management.

In addition he said that the hazard of undue lead absorption often could be markedly reduced without totally eliminating all lead-painted surfaces. For example, alternate housing might be found for the affected family rather than remodeling their existing house. However, this does not solve the problem for the next family with children that might move in. Also, alerting family members of the dangers to a young child and having them clean up flaking paint and dust could reduce the risk of exposure.

CDC said that all children ages 1 to 5 who live in or frequently visit poorly maintained buildings constructed before the 1960s should be screened at least once a year and that lead poisoning should be a reportable condition to allow more meaningful analysis at the local and national levels. The lead screening and eradication demonstration projects it has funded successfully showed the feasibility of lead poisoning control. However, according to CDC, State and local governments have generally not mounted aggressive programs. CDC officials said that most State, city, and local health department officials do not consider lead poisoning a significant problem

in their areas; but where lead poisoning screening has been done, the problem has been found to be more widespread than anticipated.

HEW advised us in April 1977 that (1) in the past year there has been increased awareness among State and local governments regarding lead poisoning in children; (2) since CDC has adequately demonstrated that lead poisoning is not confined to the so-called "lead-belt" in the cities of the Northeast, more enthusiasm has been generated; and (3) HEW has found undue lead absorption in all areas of the country, rural or urban, where a child is in association with an environment that contains lead.

The House Appropriations Committee directed CDC to take the initiative in fiscal year 1975 to help other HEW service programs incorporate routine lead screening as an integral part of the delivery of health care. Maternal and child health programs, children and youth projects, and community health centers have included lead poisoning screening in at least some of their projects but there is no reporting system or followup to determine how much screening is being done or what the results are.

In the States we reviewed, lead-poisoning screening was limited. Georgia, for example, had only one lead screening project before 1975 other than small-scale surveys in a few cities. This project, located in Savannah, had been operating for 3 years but only about 7,900 children had been screened in that period. In 1975 Georgia began its lead-based paint poisoning project, but due to limited funds the project was confined to two health districts; the project in Savannah was continued and expanded and another was begun in Augusta. In Savannah 18 percent of those screened showed elevated blood lead levels; in the other surveys, the rate was around 35 percent.

Missouri had no statewide program for lead screening. Two public health service screening projects were operating in urban areas characterized by high incidence of lead poisoning and dilapidated housing; up to 34 percent of the children screened had elevated lead levels. One of these projects had a Department of Housing and Urban Development grant for housing detoxification. At the time of our review, CDC and Environmental Protection Agency-sponsored studies were being made of airborne lead near smelters in Missouri, but results of those studies were not yet available.

California had no organized statewide lead poisoning screening program; screening was generally limited to the few counties which elected to do the testing under EPSDT as explained on page 69. Research studies have indicated that lead poisoning might be a problem. In one study, 150 or 3 percent of 5,000 children screened in Los Angeles had elevated blood levels; in one health district the incidence was 7 percent.

According to the National Association for Retarded Citizens, lead poisoning prevention programs would probably receive broader support from the public if screening were expanded beyond urban ghettos and more cases were found among children in suburbs and rural areas.

EPSDT program

HEW has emphasized including lead screening under Medicaid's EPSDT program and CDC has worked with HEW's Social and Rehabilitation Service on technical guidelines for lead screening. HEW guidelines for EPSDT state that screening programs should include, as a minimum, testing all children between the ages of 1 and 6 for lead poisoning, especially those living in old dilapidated buildings or slums.

Part of the justification for the $5.5 million decrease (from $9 million to $3.5 million) in CDC's fiscal year 1976 budget for lead poisoning prevention was that EPSDT and other health service delivery programs were to fill the gap. However, systematic wide-scale screening for lead poisoning is not being done. HEW does not even require that the number of children screened for lead poisoning under EPSDT be reported; it only requires reporting of those cases referred for diagnosis and/or treatment.

According to the fiscal year 1975 national EPSDT screening statistics, about 1.5 million children were screened for various disorders. Since the number of lead poisoning screenings performed are not reported, it is not possible to tell how many were tested for lead poisoning, but it appears that it was a small percentage of the total number of children screened. The fiscal year 1975 statistics show that, for States for which such data was available (14 States did not have the information), only about 11,900 children of 1.3 million screened were referred for diagnosis or treatment for lead poisoning. If the experience of the EPSDT program is similar to other HEW-supported screening projects which show 12.5 percent of the children screened to have elevated lead levels, it would appear that only about 95,000 children

were tested for lead poisoning--less that 10 percent ot the children reportedly screened by EPSDT. It should be noted that about two-thirds of the referrals were reported by four States.

In the States we reviewed, screening for lead poisoning under EPSDT was optional. In California, for example, each county could decide whether to include lead screening; in Missouri it was left to the discretion of each physician.

Georgia's EPSDT procedures provided that only those children who showed symptoms of lead poisoning would be tested because the State believed that it would be too expensive to test all children. However, this seems anomolous in light of previous experience which shows that only about 5 percent of those children with elevated lead levels show any symptoms and those symptoms could be so generalized that lead poisoning wouldn't normally be diagnosed unless it was already suspected. Also, irreversible damage may have occurred by the time symptoms are obvious. The State was considering extending testing to some children not showing symptoms in high-risk areas, such as those having a large number of homes constructed before 1950 and those where physicians have found lead poisoning cases.

In California and Georgia no statewide information was available on how many tests for lead poisoning were being conducted. In Missouri only 114 children out of almost 51,600 screened under EPDST during 1973 and 1974, were tested for lead poisoning.

In a 1975 preliminary report on EPDST results prepared by the staff of the Oversight and Investigations Subcommittee of the House Committee on Interstate and Foreign Commerce, 20 out of 35 State Medicaid agencies that responded to a questionnaire reported they were screening for iron deficiency anemia. As previously described, the same test can screen for both lead poisoning and anemia at the same time. Therefore, if these States were to use one of these methods in their anemia testing they could simultaneously screen for lead poisoning.

CONCLUSIONS

Excessive blood lead levels can have several adverse effects on children. One such is retardation. The principal hazards from lead comes from lead paint chips, automobile exhausts, and lead smelters.

Elevated blood levels caused by excessive lead absorption can be identified, treated, and prevented. Eliminating lead

hazards nationwide is expensive and outside the scope of our review.

Notwithstanding general efforts to clean the environment, techniques are now available to identify persons with elevated blood lead levels and treat them and identify areas where limited resources can most effectively reduce or eliminate the hazards. Neither Federal agencies nor the States, however, have taken necessary action.

Increased leadership, guidance, and efforts by HEW are needed to assure that the incidence of mental retardation (and other adverse effects) caused by lead poisoning is reduced by expanded screening to identify areas having a significant incidence of lead poisoning cases.

RECOMMENDATIONS

We recommend that the Secretary of HEW:

--Guide the States on how best to use their EPSDT programs to identify areas needing expanded lead poisoning prevention efforts; encourage the States to embark upon aggressive lead screening efforts; and support expansion of public and physician education on the problem of lead poisoning.

--Require reporting under EPSDT of the number of individuals screened for lead poisoning as well as the number referred for treatment.

--Require HEW agencies that are screening for lead poisoning to report on the results of screening to aid in identifying problem areas.

--Consider having CDC develop a surveillance system to analyze the problem at the national level.

AGENCY COMMENTS AND OUR EVALUATION

HEW concurred in part with our recommendations. HEW advised us that it is presently conducting a total review of the EPSDT program to determine optimum restructuring and that our recommendations are being addressed in that context. Our recommendations on reporting requirements are being considered in revisions being made in the current EPSDT reporting requirements.

HEW also advised us that:

"An Information Memorandum on lead poisoning is being prepared by EPSDT staff, which provides information on problems, risk, and new technology in testing for lead poisoning called the FEP (Free erythrocyte protoporphyrin). This test's low cost should encourage the States to use it. A copy of the CDC pamphlet titled, Increased Lead Absorption and Lead Poisoning in Young Children, dated March 1975, will be attached to the Information Memorandum. The pamphlet provides technical and specific information on methods used to screen, diagnose, treat and follow-up on children with increased lead absorption and lead poisoning."

HEW did not specifically comment on our recommendation that the Secretary consider having CDC develop a surveillance system to analyze the problem at the national level. The intent of this recommendation was to give HEW information on the extent of the lead poisoning problem in specific areas of the country. In revising the screening and reporting requirement of the EPSDT program HEW should require including this type of information to assist it in analyzing the problem nationwide.

CHAPTER 8

EXPANDING TESTING AND IMMUNIZATION TO PREVENT Rh DISEASE

Rh hemolytic disease can be prevented. Rh blood typing can alert Rh negative women that they are at risk; and they can be desensitized to prevent damage to any future offspring.

A 1972 Public Health Service report estimated that every year about 20,000 infants are born with Rh disease and another 5,000 pregnancies end in stillbirth. It further estimated that 5 to 15 percent of those born with the disease develop severe central nervous system complications if untreated. These complications can lead to mental retardation, hearing loss, cerebral palsy, or death. The most recent information available shows that there were 7,000 infants born in 1974 with Rh disease.

According to the National Foundation-March of Dimes, in many areas, women having an easily diagnosed need for immunoglobulin are not receiving it. Most States (1) have not established mechanisms to monitor Rh hemolytic disease, (2) do not require premarital or prenatal blood typing, and (3) do not compile comprehensive surveillance data on immunoglobulin use, Rh disease incidence, or the effectiveness of prevention efforts.

Without a continuous effort to identify Rh negative women and to provide immunoglobulin to those women who need it, this disease will not be eradicated. Federally supported family planning programs could help by typing their clients' blood for Rh factor. In addition, other Federal programs that pay for or provide delivery services could provide blood typing and vaccinate women found to be at risk.

METHODS OF PREVENTION

If an Rh positive father and Rh negative mother conceive an Rh positive baby, some of the baby's blood cells may get into the mother's blood stream during birth, causing the mother's body to produce Rh antibodies. If the mother conceives a subsequent Rh positive baby, the maternal antibodies can attack and destroy the baby's blood cells causing jaundice, mental retardation, deafness, anemia, cerebral palsy, seizures, or death.

Damage can be prevented in two ways. Rh positive babies found to have Rh disease can be treated by being given massive blood transfusions shortly after birth to replace their damaged

blood cells with new healthy cells. The preferred method, though, is to prevent the disease by giving Rh negative mothers immuno globulin--a serum licensed in 1968 which prevents the production of the Rh antibodies. If an Rh negative mother's body has not already developed antibodies by having Rh positive children and if she is given immunoglobulin within 72 hours after having an Rh positive baby or following miscarriage or abortion, any future Rh positive babies will be free from danger of Rh disease.

Whatever method used, the initial step in prevention is typing the mother's blood. Women found to be at risk can then be monitored closely during pregnancy and the appropriate techniques used to avoid damage to their babies.

LACK OF COMPLETE NATIONAL INFORMATION ON INCIDENCE AND IMMUNIZATION

Aside from local efforts, little has been done to compile and evaluate data on Rh hemolytic disease prevention. Rh disease is not on CDC's list of reportable diseases and according to a 1974 CDC report only

--5 States had mechanisms for fully monitoring Rh hemolytic disease,

--7 States required by law either premarital or prenatal blood typing, and

--6 States had special programs for reporting immunoglobulin utilization.

The absence of accurate and complete national surveillance data precludes any accurate determination of the incidence of mental retardation resulting from Rh hemolytic disease. Subsequent to the completion of our fieldwork, we were informed by HEW that two surveillance reports have been published which compile available national data which is fragmentary but does show the need for better national data.

In Georgia, State officials did not know the extent of the Rh problem because

--there was no Rh disease surveillance program,

--Rh blood typing was not required to obtain a marriage license, and

--abortion clinics were not regulated or licensed by the State.

Missouri did not require Rh testing before marriage, testing pregnant women for Rh, or reporting Rh disease of the newborn, although some information on Rh complications was available from birth certificates. Missouri did not require abortion clinics to report information on Rh typing and administration of Rh immunoglobulin to Rh negative women.

California had no statistics on the number of patients placed in community care facilities for the retarded due to Rh disease, but we did obtain the number of residents in State institutions for the retarded suffering from kernicterus, the major complication resulting from Rh disease. In 1975 there were 89 residents, just under 1 percent of the total State institutional population.

Forty-nine States and the District of Columbia (Maryland did not report) reported a total of 320 infant deaths in 1974 due to Rh disease. As part of CDC's Birth Defects Monitoring Program, 1/ 1,200 participating hospitals, which account for about one-third of the births in the United States annually, reported a total of 2,660 cases of Rh disease in 1973 and 2,426 cases in 1974.

UNDERUTILIZATION OF RH IMMUNOGLOBULIN

National statistics of the number of women at risk who are not receiving immunoglobulin are not available, but studies and estimates indicate many women who need the globulin are not getting it. In a 1976 report, CDC estimated, based on the number of immunoglobulin doses sold by U.S. manufacturers, that in 1974, about 80 percent of the 449,100 women estimated to need the serum were receiving it; leaving about 91,300 women a year at risk. Various reports show that the utilization rate is uneven among the States and that particular problems exist in rural areas and for abortions.

In May 1975 at a symposium on Rh disease, representatives of the University of North Carolina reported on the

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1/A voluntary surveillance program jointly sponsored by the Commission on Professional and Hospital Activities, the National Foundation-March of Dimes, the National Institute of Child Health and Human Development, and CDC.

results of five studies conducted between 1971 and 1974 on immunoglobulin use following deliveries or abortions. Overall, the studies revealed that only 57 percent of the women at risk received the serum. This report further stated that, even assuming an 80-percent utilization rate, given 3 million live births and 1 million abortions a year, 1/ about 12,000 women each year are added to the group of over 250,000 women in their child-bearing years who have developed Rh anti bodies and are therefore at risk for having damaged children.

One of these studies of a demonstration project at an abortion clinic in Washington, D.C., showed what can be achieved by aggressive prevention efforts. The project was designed to achieve maximum use of immunoglobulin following abortion. During the 7-week study, 255 (96 percent) of the 265 Rh negative women received the serum. Of those who did not, six refused because they were going to be sterilized and the other four reportedly had Rh negative mates, so they were not at risk for having an Rh positive child.

REQUIRING BLOOD TYPING APPEARS TO HELP

Of the States we reviewed, only California required blood typing or monitoring of Rh disease. California's law required Rh blood typing for all pregnancies, even those ending in miscarriage or abortion, and reporting of all cases of Rh hemolytic disease. The law appears to have helped reduce the incidence of Rh hemolytic disease. Since 1970 when the law went into effect, the total reported incidence of Rh disease dropped from 1,524 cases to 515 cases in 1974; reported infant deaths dropped from 97 in 1970 to 8 in 1974.

In the other States we reviewed, the incidence appears to be much higher. For example, a 1975 CDC report showed 11 infant deaths in Georgia due to Rh hemolytic disease in 1973. There were 23 deaths that year in California, which has over three times the number of annual births as Georgia. In Missouri, a State review of birth certificates and fetal death certificates identified 463 complications of pregnancy in 1974 due to Rh sensitization compared to 515 cases in California; California has more than four times the annual number of births as Missouri. Also, the actual number of Rh complications in Missouri may have been much greater than

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1/The authors recognized that the rate for abortions may have been overestimated.

the 463 cases reported because the State has found that hospitals and physicians were not providing complete data on about 50 percent of the birth and fetal death certificates.

Although California's law does not require reporting of immunoglobulin use, this rate also appears to be higher than in the other States we reviewed. For example, a California department of health study of 11 hospitals revealed that of 183 women who were considered candidates for immunization, all but 6 received immunoglobulin. Of those who did not, five were going to be sterilized and the sixth simply refused.

A health official in Georgia stated that, in his opinion, practically all Rh negative women in the State were receiving immunoglobulin without a mandatory State surveillance program. However, a 1972 report by a CDC researcher, the most recent study available, covering nine rural Georgia hospitals, showed that an average of only 62 percent of the women at risk following full-term delivery received serum. In one hospital, the rate was zero and in two others less than one-third of the women at risk received the serum.

The report stated that for abortions the situation was worse. In six hospitals, Rh immunoglobulin was given on the average to only 42 percent of the women at risk. The report cited two barriers to optimal serum use following delivery or abortion: (1) if no prenatal Rh blood typing is performed, the women at risk may not be identified and (2) physician's and patient's lack of awareness of the need for the globulin, particularly following abortion.

Missouri had no requirement for making Rh immunoglobulin available to Rh negative women. No data was available to show the number of Rh negative women receiving immunoglobulin. Missouri health officials we interviewed thought that Rh compatability testing and provision of immunoglobulin was a matter for the women's private physician and that it was already routinely done. However, the incidence of Rh complications cited above indicates that this is not necessarily true.

FEDERAL PROGRAMS COULD HELP

In January 1976, the Deputy Director of CDC's Birth Defects Division prepared a position paper on the prevention of Rh disease. He pointed out that:

--There is a persistent lack of data concerning the use of immunoglobulin following spontaneous and therapeutic abortions.

--Without this data there should be continued concern that many Rh negative women are not receiving immunoglobulin and are becoming sensitized (developing antibodies).

--In view of these circumstances, there is a need for a concerted national and local effort to assure complete use of Rh immunoglobulin where indicated following all deliveries and abortions.

The Deputy Director's paper stated that there is a need for national leadership in highlighting the continuing problems of Rh hemolytic disease and need for immunoglobulin and suggested that:

--Each hospital with obstetrical services implement a system to insure that every pregnant woman has an Rh determination.

--Immunoglobulin be given to Rh negative women when needed.

--Provision be made for compiling data that each hospital can use to assess its program and quickly identify breakdowns or other barriers to immunoglobulin administration.

An approach suggested in the paper would be to specify to States the elements needed for a community Rh prevention program and give examples of how some States (Connecticut, California, Illinois, New Jersey, Colorado) have developed programs. States and communities could use this information to plan the approach most suited to their own needs. Consultation could be given by CDC and through maternal and child health programs. Data compiled at the community level could be sent to CDC for incorporation into the Rh Disease Surveillance Report, thus providing progressively better assessment of Rh disease prevention.

The paper further stated that the details of a hospital information system are being developed which would insure that all information needed to make an informed decision regarding immunoglobulin use is made on each woman delivering a baby or having an abortion. This information, properly organized and collected, can be used to evaluate the success (or failure) of the hospital system.

The medical director of California's department of health developmental services program, treatment services

division, stated that Federal programs could help prevent Rh disease by requiring (1) Rh testing in every pregnancy where the prenatal care or delivery is paid for through Federal programs, such as maternal and child health, and (2) all hospitals with obstetric services that receive or have received Federal funds for construction, training, or operations to include Rh typing in every delivery, miscarriage, or abortion and implement a system for reporting Rh disease and immunoglobulin use.

Federally funded family planning programs could also help. As discussed on page 59, blood testing is a routine part of family planning services. According to a 1973 publication, the "Economics of Mental Retardation," where a blood sample is already being taken for other purposes, Rh typing could be added for pennies more. However, the family planning programs we contacted did not routinely screen couples for Rh incompatibility.

CONCLUSIONS

Mental retardation and other complications caused by Rh hemolytic disease can be prevented through aggressive actions to identify Rh negative women and provide them with immunoglobulin when they bear Rh positive children or have abortions. Although the extent of the problem is not known, many women apparently are not receiving immunoglobulin. The extent of the problem could be more accurately determined if more States had comprehensive systems for testing pregnant women for Rh imcompatability, reporting disease incidence, and reporting immunoglobulin utilization. In lieu of State laws requiring such tests, the family planning programs could assist by including Rh blood typing as a routine part of family planning services.

RECOMMENDATIONS

We recommend that the Secretary of HEW:

--Instruct CDC to determine if the incidence of Rh disease is lower in States having mechanisms for monitoring Rh disease and immunoglobulin use. If such surveillance mechanisms are effective, encourage States to develop comprehensive systems to test all pregnant women for Rh incompatibility and report incidence of Rh hemolytic disease and use of Rh immunoglobulin to CDC, thereby establishing a national program for monitoring the incidence of the disease.

--Require federally supported family planning programs to include Rh blood typing as a routine part of family planning services.

--Encourage Rh testing in all deliveries, miscarriages, or abortions paid for with HEW funds and provide immunoglobulin to women who need it.

AGENCY COMMENTS

HEW agreed with our recommendations. The Department stated that CDC is offering consultation to States upon request by helping them determine the nature of the problem and offering possible solutions.

With respect to our recommendation that federally supported family planning programs be required to include Rh blood typing as a routine part of their services, HEW advised us that (1) Rh type should be considered an essential component of every woman's personal health knowledge; (2) Rh typing could be provided through several Federal programs; and (3) if a client has not been previously typed and presents herself at a family planning clinic, this will be included as a routine part of family planning services.

HEW also advised us that, with respect to our recommendation that it encourage Rh typing in all deliveries, miscarriages, or abortions paid for with HEW funds and providing immunoglobulin to women who need it, programs supported through title V funds are encouraged to include prevention of Rh disease in all programs. Also, although title XIX (Medicaid) standards are set by the State, the Department urges comprehensive service availability.

CHAPTER 9

IMPROVING EARLY CHILDHOOD EXPERIENCES

Although the exact relationship between poor living conditions and mental retardation is still not fully understood, many research and demonstration projects and programs have been implemented. However, these efforts have not been systematized at either Federal or State levels. None of the HEW agencies we contacted felt it was their direct responsibility to collect and evaluate the results of various programs aimed at preventing psychosocial retardation or implementing those that are the most efficient and effective. As a result, little is known about the full extent of ongoing programs, how many people are being reached, or whether the techniques being used are effective and could be more widely applied.

The previous six chapters of this report have discussed clinical causes of mental retardation which are generally more severe and costly. However, as indicated in chapter 1, it is generally estimated that approximately 75 percent of the incidence of mental retardation can be attributed to adverse environmental conditions during early childhood. While these cases are generally less severe, they do account for the largest number. Preventive methods, however, are less clear-cut for psychosocial retardation than for clinical causes.

PREVENTIVE TECHNIQUES

Developing massive programs to overcome the problems of millions of impoverished citizens is clearly beyond the scope of what can be done in the foreseeable future. According to the National Institute of Child Health and Human Development, a more feasible approach involves identifying the most critical factors in early childhood development, the changes in a child's daily living experiences which would help prevent intellectual and behavioral shortcomings, and when and for how long intervention should occur.

Two approaches appear to help prevent this cause of retardation--educating parents on better child-rearing practices and providing the stimuli to high-risk infants which are missing from their environments.

Parent education

According to some authorities, one means of preventing psychosocial retardation is by equipping parents with good child-rearing skills. Ignorance of important facts involving

a child's development is especially acute in young unwed mothers, minority groups, and low-income families. Also, parents of lower intelligence do not readily recognize delayed development in their children.

There are no definite guidelines on the best way to raise children, but certain techniques appear to be relevant to healthy intellectual and social development. One study of early childhood development, the Harvard Preschool Project, was funded in part by the Office of Education and conducted by the Harvard Graduate School of Education. The study focused on the experiences of children from birth to age 6 in the environment of their own homes.

The researchers identified certain child-rearing techniques used by mothers of children who developed well and which appeared to be significant factors in that development. The study indicated that more research is needed to determine the most effective child-rearing practices, but that much more is known now than is generally taught to parents. Furthermore, what little is available is not readily available.

The researchers concluded that few, if any, modern societies make extensive efforts to prepare and assist their families to raise children and that we must pay considerably more attention to child-rearing practices.

Early intervention

One of the more widely publicized studies of early intervention was a research and demonstration project funded by HEW's Rehabilitation Services Administration, the "Milwaukee Project." The study, which cost an estimated $1.7 million, was done by the Waisman Center for Retardation in Madison, Wisconsin. The researchers selected women from a run-down metropolitan area of Milwaukee previously identified as having a high prevalence of retardation. Training programs were designed for the mothers in the experimental group which included instructions in mothering, child care, and homemaking. In addition, trained professionals assisted the families in child-rearing activities and enriching the children's early experience.

Throughout the term of the project, the children of the experimental group and the control group were repeatedly tested. The children in the experimental group developed intelligence quotients which averaged about 25 points higher than those in the control group. The researchers concluded that early and

intensive stimulation and education intervention can minimize developmental problems normally presented by high-risk children when they attain school age.

ONGOING PROGRAMS HAVE
NOT BEEN SYSTEMATIZED

In the States reviewed, we identified many programs which included parent education and/or early intervention. However, information on the results or effectiveness of these programs was not being centrally or systematically collected and evaluated. Most State health and education officials we contacted were unaware of the extent, scope, or content of programs in their States. For example, we identified several programs in Missouri that included education on childhood development, but State officials had no information on the scope, content, or design of the programs and told us that we would have to obtain such information from the projects themselves. Although we found several programs and projects in Missouri which appeared to include early intervention, the director of the Missouri division of health stated that the adequacy of the intervention programs is still to be determined.

The director of special education projects for Missouri told us that the department of elementary and secondary education provided funds to local school districts to operate programs for 3 and 4 year olds. However, information concerning the programs' format was not required to be submitted to the State so he had no information on individual program content; he did not even have a list of the districts that had such projects.

In California, there were several private and publicly supported programs designed to enhance early childhood development. California's department of education operates several programs directed at parent education and early childhood development including: Early Childhood Education Outreach, preschool programs, the School Age Parenting and Infant Development Program, and the Child Development Programs. However, education officials said that no standards had been set up or evaluations done to measure their impact. Also, since the programs of the department of education were administered at the school district level, and since each school district was autonomous, the individual program approaches varied.

One California health official said his department had been reluctant to implement widespread intervention programs

because they were not yet convinced of the programs' merits. He cited the inconclusiveness of the developmental testing methods used, especially testing based solely on intelligence quotient measurement. An additional drawback he saw was that the state-of-the-art of child development and early intervention techniques is unclear and experts in the field disagree on proper intervention methods.

In Georgia, the State director of physical health told us that very little was being done to educate parents and to identify and intervene with high-risk infants. Other State and HEW regional officials interviewed said they believed there were such programs operating in the State, but they could not identify them. For example, Region IV's Coordinator for Education and Community Services said that there were various education programs to help parents properly develop their children, but they varied by State and State officials would have to be contacted to obtain specific information.

We identified several programs in Georgia which appeared to include education on childhood development, such as the Parent Education Demonstration Projects funded by the Office of Education, and programs offered through State-supported child development centers, but State officials had not collected or evaluated information on the programs' design or what they included.

THE NEED FOR FEDERAL EVALUATION OF PREVENTION TECHNIQUES

Several Federal studies have been made to identify research and intervention programs throughout the country. One study completed under an HEW contract in 1972 to assess the delivery of early intervention programs to potentially retarded children identified more than 40 longitudinal intervention research programs for high-risk children.

In 1974, the National Leadership Institute/Teacher Education at the University of Connecticut completed a survey to determine what programs for children under 3 years of age were operating or proposed. Information was solicited from several sources, including State departments of education, State offices of child development, and early education program directors. A total of 53 ongoing and proposed programs were identified operating at 116 sites and involving about 19,000 children and their families. Additionally, 8 universities and 23 community colleges were involved in infant and toddler research and service programs.

The Office of Child Development, the Office of Education, and the National Institute of Mental Health jointly sponsored a program to help teenage boys and girls prepare for parenthood through learning about child development and working with young children. As part of the program, a workstudy curriculum in child development was developed for secondary school students. The course was tested in 234 schools during the 1973-74 school year and in 1975 was being started in about 1,000 schools, universities, and other organizations throughout the country.

Aside from these efforts, no single agency within HEW assumed responsibility for systematically evaluating the results of such programs or for seeing that effective techniques are implemented. In 1972, an HEW contractor reported on the status and results of intervention research projects funded from a variety of private and Federal sources including the Office of Education, the Office of Child Development, and the National Institute of Mental Health. The report stated that (1) there is no centralized system to guide and orchestrate the various longitudinal intervention research activities being conducted, (2) in most respects, the area is actually understudied in light of the research results obtained and the promise they show, especially with very young children with moderately low intelligence quotient scores, and (3) no significant studies were being conducted to evaluate the social and cost benefits of intervention with potentially retarded preschool children.

A report prepared by the National Institute of Child Health and Human Development for presentation to the National Advisory Child Health and Human Development Council in 1973 stated:

> "Too little attention has been given to the damaged and at risk infant, and we need to know much more about the interaction effects operating in his early development as building blocks to intervention programs. In particular, we need to systematize this work and make it at once whole with objectives of our goal-optimal intervention for the damaged and risk infant and child."

The outcome of the Milwaukee Project is an example. After 10 years of operation, Federal funding of the study lapsed. No systematic evaluation has been made of the study's results to determine if the techniques used are effective or could be implemented in other Federal programs. Rehabilitation Services Administration officials believed the study results were of great value and that it should be continued, but attempts by

that agency and PCMR to have other HEW programs continue funding of that or similar projects have been unsuccessful.

A Rehabilitation Services Administration official told us that agency had not continued that or similar projects because it was outside the scope of its responsibility. No clearcut reasons could be given as to why other agencies had not picked up project funding except that PCMR had apparently been unable to generate enough interest in it and no other agency felt that the project fell directly under its responsibility.

An October 1975 seminar, jointly sponsored by the University of Wisconsin, PCMR, the National Association for Retarded Citizens, and HEW, pointed to a need to identify the most effective early childhood intervention techniques, coordinate researchers and practitioners to solidify research data and implement research results, and implement evaluation and assessment systems.

CONCLUSIONS

Since the majority of the incidence of retardation is attributable to adverse early childhood experiences, any effective prevention strategy must address these causes. Although many studies and projects have been undertaken in this area, HEW has not established a strategy or fixed responsibility for identifying, evaluating, and implementing the most effective and cost beneficial parent education and early intervention techniques or for coordinating the work of researchers and practitioners.

RECOMMENDATIONS

We recommend that the Secretary of HEW:

--Fix responsibility for (1) collecting results of studies of parenting education and early intervention techniques and programs that have used these preventive measures and (2) evaluating their success.

--Identify (1) areas in most need of study and (2) most effective and cost beneficial methods of prevention.

--Disseminate information developed from evaluation of studies and programs to other Federal and State agencies for consideration in implementing their programs.

AGENCY COMMENTS AND OUR EVALUATION

HEW in commenting on a draft of this report did not comment on our specific recommendations but advised us that the issues will be addressed when the specific focal point in the Office of the Assistant Secretary for Health is designated.

APPENDIX I

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
OFFICE OF THE SECRETARY
WASHINGTON, D.C. 20201

JUL 25 1977

Mr. Gregory J. Ahart
Director, Human Resources
Division
United States General
Accounting Office
Washington, D.C. 20548

Dear Mr. Ahart:

The Secretary asked that I respond to your request for our comments on your draft report entitled, "Preventing Mental Retardation: More Can be Done." The enclosed comments represent the tentative position of the Department and are subject to reevaluation when the final version of this report is received.

We appreciate the opportunity to comment on this draft report before its publication.

Sincerely yours,

Thomas D. Morris
Inspector General

Enclosure

COMMENTS OF THE DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE ON THE COMPTROLLER GENERAL'S DRAFT REPORT TO THE CONGRESS OF THE UNITED STATES ENTITLED "PREVENTING MENTAL RETARDATION: MORE CAN BE DONE"

General Comments

We are in general agreement with the draft report.

We find the conclusions contained in the draft report valid and the recommendations worthy of implementation. Further, it reflects an approach which has characterized the Department's activities since the President's Panel on Mental Retardation reported its conclusions in 1962.

Since that time, the Department has focused its efforts on those selected causes of mental retardation identified in the report, e.g., metabolic disorders, prematurity and low birth weight, chromosome abnormalities, rubella and measles, lead poisoning, Rh hemolytic diseases, and early childhood experiences. It also supported research directed to a better understanding of other factors associated with mental retardation (MR). The GAO report is inadequate in its attention to research programs and fails to recognize the necessity for research to reduce the incidence of mental retardation. A limited description of the Department's research program underplays its significance in attacking the causes of mental retardation. Research is needed in the areas of genetics, abnormal fetal growth, birth trauma, prenatal infection, malnutrition (all biologic causes of mental retardation), and psychosocial deprivation (80% of mental retardation stems from the influence of an unfavorable environment). In addition, within the framework of the existing service delivery system, current knowledge and techniques on how preventive service delivery can be extended to a larger segment of the risk population, and how the delivery can be made more effective and efficient through leadership and coordination have been addressed by the Department. HEW delivers services only to a small minority of the at-risk population. If the goal of reducing MR by 50% is to be achieved, the private sector must be involved along with public health programs.

While the draft report is clearly focused on a preventive effort related to known biomedical causes, Chapter I of the report tends to somewhat confuse the focus by addressing the broad problem of mental retardation and to some extent leading to an expectation that subsequent sections of the report might also address some of the issues of research, training, or the sociocultural aspects of mental retardation.

GAO RECOMMENDATIONS

GAO recommends that the Secretary of HEW:

1. Designate a focal point in HEW to implement a national prevention strategy, monitor and coordinate the efforts of the various HEW agencies and offices, and develop a method of determining the progress being made in reaching the goal.

2. Designate prevention of mental retardation as an objective in HEW's operational planning system.

DEPARTMENTAL COMMENTS

1. We concur. The focal point for the Department will be in the Office of the Assistant Secretary for Health (OASH). The specific office within OASH will be designated by the Assistant Secretary for Health.

2. We will consider including the prevention of mental retardation as an objective if the operational planning system is continued. Whether the departmental system is continued or not, the relevant issues will be monitored by the agency tracking system.

GAO RECOMMENDATIONS

GAO recommends that the Secretary of HEW help improve newborn screening by:

1. Determining what is needed to improve the coverage and effectiveness of newborn screening programs and assisting States in improving their programs.

2. Encouraging and supporting expansion of newborn screening to include other treatable metabolic disorders in addition to PKU.

3. Encouraging and assisting States to cooperate in establishing cost-effective regionalized metabolic screening programs.

Department Comments

1. We concur. The PHS Child Health Strategy addresses those issues, as do the implementation plan for the Genetic Diseases Act and ongoing activities described in response to the next two recommendations. In a few States, hospitals still have the option of using private laboratories and reporting is difficult. Some States, for example, with only 6,000 births per year and whose laboratory capacity limits their testing to the simple Guthrie procedure for Phenylketonuria, find it uneconomical to expand their screening for additional conditions, such as hypothyroidism, which would involve the purchase of additional expensive equipment. Many States hesitate to include other conditions in their screening

programs, such as Maple Syrup Urine Disease, because of a concern about their ability to provide adequate treatment services for those infants that might be detected (i.e., available genetic centers to manage and monitor the infant and to purchase and provide the amino acid dietary products).

2. We concur. This encouragement and support takes several forms, such as technical assistance to State Health Department laboratories as to how the same blood spot on filter paper could be used to test for multiple conditions, providing some additional equipment to automate procedures, developing guidance material on laboratory screening procedures, treatment, and management. Additional support for the genetic centers (generally genetic units at medical centers to which States refer positive screening results for management) would considerably encourage States to expand their screening efforts if they could be assured that these centers they have designated could handle the increased load. At the moment, there is considerable interest in hypothyroid screening for which effective treatment and management may be comparatively simple compared to the other conditions. The full implementation of Title IV of the Genetic Diseases Act by the Bureau of Community Health Services should enhance the capability of the genetic centers and encourage a number of States to expand their newborn screening.

3. We concur. Regional Newborn Screening Laboratories facilitate quality control and permit economies of scale. Consequently, they are the most cost effective approach. Two major Regional Newborn Screening Laboratories have been established with the assistance of the Maternal and Child Health Programs, BCHS. The Massachusetts State Health Department Laboratory by contractual agreement is screening all of the newborn samples from the New England States, except Connecticut, for five different conditions. The Oregon State Health Department has similar arrangements with the States in the northwest. At the moment, California is in the process of setting up three regional laboratories for the State. Ohio and North Carolina are interested when start up costs are available. Other States are being encouraged to participate in regional systems through HEW-funded university affiliated centers and genetics projects.

GAO RECOMMENDATIONS

To be able to establish priorities for the allocation of prenatal care funds in the most effective manner and to the areas of greatest need, GAO recommends that the Secretary of HEW direct the Bureau of Community Health Services to:

1. Evaluate the State procedures used to determine needs for prenatal care services and insure that State plans outline a clear strategy of how to reach the population in greatest need.

(See GAO note on p. 96.)

Department Comments

1. We concur. Delegation of responsibility for Title V of the Social Security Act to BCHS has included the responsibilities contained in the recommendation. The maternity and infant care projects program, established by the Maternal and Child Health Programs, was targeted on high risk populations (pregnant women in low income areas who had previously received little or no prenatal care). While these programs provided such care and demonstrated an ability to decrease the infant mortality, they only provided for follow-up of the newborn infant for one year and hence were never able to document outcome in terms of the ultimate goal of reducing mental retardation. Based on a State-by-State assessment of high infant mortality and morbidity distribution, BCHS has initiated Statewide Improved Pregnancy Outcome projects in 9 states. An additional 9 are projected for fiscal year 1977. HSA is aware that in many States the unmet need for prenatal care has not been sufficiently analyzed (pp. 44-47). In fact, the assessment of health service needs of mothers and children in all States is an element of HSA's Child Health Strategy for fiscal year 1978-1982.

(See GAO note on p. 96.)

GAO RECOMMENDATIONS

GAO recommends that the Secretary of HEW:

1. Direct federally supported family planning programs to include, as a routine part of their services, screening for individuals who are "high risk" for genetic disorders and refer such individuals to diagnostic and counseling services.

2. Monitor the demand on existing genetic resources created by outreach and develop strategies for increasing resources as needed.

3. Explore how other Federal programs could better be used to provide genetic screening and services.

Department Comment

1. We concur, in principle, but can not mandate universal screening until more capacity for effective screening and counseling is available. Family Planning Program Guidelines recommend these as clinic services where available.

   The demand on existing genetic resources at present exceeds their capacity. It is estimated, for example, that only 10,000 prenatal diagnoses were provided by existing genetic resources in 1976. Twenty genetic centers provided almost half of these evaluations.

2. We concur. The continued monitoring of the demand on existing genetic resources is most important in implementing these recommendations to assure that the demands generated by any outreach and additional screening can be dealt with by the centers. Both the Child Health Strategy and the Genetic Diseases Implementation Plan stress State-wide networks with the State Health Department playing the key role in establishing linkages between screening and provider programs.

3. We concur. Now that the focal point has been established, it will be possible to work out a mechanism to include these activities in other Federal programs.

GAO RECOMMENDATIONS

GAO recommends that the Secretary of HEW:

1. Examine the alternative of expanding the Center for Disease Control support of State vaccination programs, or making arrangements between CDC and the Social and Rehabilitation Service that will enable EPSDT to more effectively support national and State immunization activities.

2. Expand EPSDT requirements to specifically require screening for immunization status and reporting of the number of screened and the number immunized.

3. Require Head Start projects to develop data on the results of their immunization screening.

4. Require federally funded family planning and other appropriate programs to include rubella susceptibility testing and immunizations,

where appropriate, among their routine services.

Department Comments

We concur. The draft proposed revision to the EPSDT Penalty Regulation will require that the immunization status of each Medicaid recipient be determined at the time the screening test is performed. Revisions to current reporting requirements are in process and include reporting on inadequate immunization status found through screening.

The Department has proposed to Congress on April 25, 1977 legislation to convert EPSDT to a Comprehensive Health Assessments and Primary Care for Children Initiative which will address these issues. This has been introduced as H.R. 6706 and S. 1392.

References in the draft (pp. 63-64) to the United States Immunization Survey should be reviewed. CDC has completed an evaluation of this survey; changes which the evaluation report recommended to improve accuracy have been approved and the Bureau of the Census, which conducts the survey for CDC, has implemented the changes. More aggressive vaccination efforts are needed and the Department is currently planning for them to include better coordination at a local level of the CDC effort with EPSDT, Head Start, Child Find, and the Maternal and Child Health delivery system.

While the recommendation that the federally funded family planning program be required to include rubella susceptability testing is generally compatible with improved prevention of Rh disease, the usefulness of Rh typing in family planning clinics and in premarital serologics remains to be shown. The critical time to identify the Rh negative woman is prior to birth of her child or at abortion. Screening at other times should be shown to be cost effective before adoption as a recommended public health measure.

GAO RECOMMENDATIONS

GAO recommends that the Secretary of HEW:

1. Provide guidance to the States on how best to use their EPSDT program to identify areas needing screening for lead poisoning; encourage the States to embark upon aggressive lead screening efforts; and support expansion of public and physician education on the problem of lead poisoning.

2. Require reporting under EPSDT of the number of individuals screened for lead poisoning as well as the number referred for treatment.

3. Require HEW agencies that are screening for lead poisoning to report on the results of screening to aid in identifying problem areas.

4. Consider having CDC develop a surveillance system to analyze the problem at the national level.

Department Comments

We concur in part. In addition to recommending improvements in the EPSDT program through changes in the enabling legislation, the Department is reviewing current program operations to achieve optimum performance. These issues are being addressed in that context.

An Information Memorandum on lead poisoning is being prepared by EPSDT staff, which provides information on problems, risk, and new technology in testing for lead poisoning called the FEP (Free erythrocyte protoporphyrin). This test's low cost should encourage the States to use it. A copy of the CDC pamphlet titled, Increased Lead Absorption and Lead Poisoning in Young Children, dated March 1975, will be attached to the Information Memorandum. The pamphlet provides technical and specific information on methods used to screen, diagnose, treat and follow-up on children with increased lead absorption and lead poisoning. On page 1 of this CDC document, definitions of "Lead Poisoning", "Undue or Increased" "Lead Absorption" and "Toxicity" used by the Department are set forth. We recommend that GAO use these definitions in the body of this chapter in order to clarify the recommendations.

Reporting requirements in the recommendation are being considered in the revisions being made to the current reporting requirements for EPSDT. The age group most vulnerable to the ill effects of excess lead, 18 months to 3 years, is also the group most likely to suffer from iron deficiency anemia (up to 40% in lower socio-economic groups). Hence, for every suspicious case detected by protoporphyrin measurements, it will be necessary to rule out iron deficiency as a cause for high protoporphyrin levels while remembering that both may co-exist.

Preliminary analysis of the problem by CDC documents lead in dust as one of the current major problems. A variety of sources, such as lead based paint on the exterior of buildings, automobile emissions, fumes from industrial plants, etc. all contribute to this airborne lead. While the ideal long range solution of the problems of lead poisoning would be elimination of all environmental sources of lead, the more immediate public health approach requires a continuing effort at screening detection and correction of episodic problems.

GAO RECOMMENDATIONS

GAO recommends that the Secretary of HEW:

1. Instruct CDC to determine if the incidence of Rh disease is lower in States having mechanisms for monitoring Rh disease and immuno-

globulin use. If such surveillance mechanisms are effective, encourage States to develop comprehensive systems to: test all pregnant women for Rh incompatibility, report incidence of Rh hemolytic disease and use of Rh immunoglobulin to CDC, thereby establishing a national program for monitoring the incidence of the disease.

2. Require federally supported family planning programs to include Rh blood typing as a routine part of family planning services.

3. Encourage Rh testing in all deliveries, miscarriages, or abortions paid for with HEW funds and providing of immunoglobulin to women who need it.

Department Comments

1. We concur. CDC is involved in the monitoring and surveillance of Rh disease. It offers consultation to States upon request by helping them determine the nature of the problem and offering possible solutions.

2. We concur. Rh type should be considered an essential component of every girl's personal health knowledge. Rh typing could be provided through several Federal programs as are immunizations currently. If a client has not been typed and presents herself at a family planning clinic, this will be included as a routine part of family planning services.

3. We concur. Programs supported through Title V funds are encouraged to include prevention of Rh disease in all programs. Title XIX standards are set by States and while the Department urges comprehensive service availability, the decision ultimately rests with the States.

GAO RECOMMENDATIONS

GAO recommends that the Secretary of HEW:

1. Fix responsibility for (1) collecting results of studies of parenting education and early intervention techniques and programs that have used these preventive measures and (2) evaluating their success.

2. Identify (1) the areas in most need of study and (2) the most effective and cost beneficial methods of prevention.

3. Disseminate information developed from evaluation of studies and programs to other Federal and State agencies for consideration in implementing their programs.

Department Comments

These issues will be addressed when the specific focal point in OASH is designated.

GAO note: Deleted material refers to matters not discussed in this final report. Page references in this appendix may not correspond to page numbers in the final report.

APPENDIX II

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
WASHINGTON, D.C. 20201

February 15, 1977

Mr. Gregory Ahart, Director
Human Resources Division
United States General
Accounting Office
441 G Street, N.W.
Room 6864
Washington, D.C. 20548

Dear Mr. Ahart:

The President's Committee on Mental Retardation commends you on the recent report "Preventing Mental Retardation: More Can Be Done." The report was the subject of a meeting of our Task Force on Biomedical Prevention which included representatives of the American Association on Mental Deficiency, and the National Association for Retarded Citizens.

The Task Force was thus able to respond verbally to Mr. Frank Ackley of your staff.

In addition we have shared the report with all Committee Members as a way of keeping them informed on this vital subject.

The GAO staff members who worked on this were "quick studies" who, coming from a discipline outside the realm of mental retardation, were able to absorb both the facts and the issues and arrive at sound recommendations.

We cannot emphasize too much that prevention of mental retardation is both cost beneficial and cost effective and would underscore the report's emphasis on this area.

While we recognize that it was not possible to cover each and every one of the more than 200 causes of mental retardation the report does speak to the categories which group the many specific disorders causing mental retardation, and is consistant with the AAMD manual on terminology and classification.

APPENDIX II

PCMR will be meeting with representatives of each of the Departments of Federal Government in order that each Department may identify those programs they will initiate, or expand in order to make significant contributions to reducing the incidence of mental retardation.

PCMR will also keep up to date on DHEW's progress in prevention.

We concur with the recommendations of the report, and thank you for the opportunity to review this document.

Sincerely,

Fred J. Krause
Executive Director

Allen R. Menefee
Assistant Director, Program

PRINCIPAL HEW OFFICIALS RESPONSIBLE FOR ACTIVITIES DISCUSSED IN THIS REPORT

	Tenure of office	
	From	To
SECRETARY OF HEW:		
Joseph A. Califano, Jr.	Jan. 1977	Present
David Mathews	Aug. 1975	Jan. 1977
Caspar W. Weinberger	Feb. 1973	Aug. 1975
Frank C. Carlucci (acting)	Jan. 1973	Feb. 1973
Elliot L. Richardson	June 1970	Jan. 1973
ASSISTANT SECRETARY FOR HEALTH:		
Julius Richmond	July 1977	Present
James F. Dickson III (acting)	Jan. 1977	July 1977
Theodore Cooper	May 1975	Jan. 1977
Theodore Cooper (acting)	Feb. 1975	Apr. 1975
Charles C. Edwards	Mar. 1973	Jan. 1975
Richard L. Seggel (acting)	Dec. 1972	Mar. 1973
Merlin K. Duval, Jr.	July 1971	Dec. 1972
ASSISTANT SECRETARY FOR HUMAN DEVELOPMENT:		
Arabella Martinez	Jan. 1977	Present
Stanley B. Thomas, Jr.	Aug. 1973	Jan. 1977
Stanley B. Thomas, Jr. (acting)	Apr. 1973	Aug. 1973
ADMINISTRATOR, SOCIAL AND REHABILITATION SERVICE:		
Don I. Wortman (acting)	Jan. 1977	Mar. 1977
Robert Fulton	June 1976	Jan. 1977
Don I. Wortman (acting)	Jan. 1976	June 1976
John A. Svahn (acting)	June 1975	Jan. 1976
James S. Dwight, Jr.	June 1973	June 1975
Francis D. DeGeorge (acting)	May 1973	June 1973
Philip J. Rutledge (acting)	Feb. 1973	May 1973
John D. Twiname	Mar. 1970	Feb. 1973
ADMINISTRATOR, HEALTH CARE FINANCING ADMINISTRATION:		
Robert A. Derzon	Apr. 1977	Present
Don I. Wortman (acting)	Mar. 1977	Apr. 1977

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